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TITLE: Mobile Phone Technology to Increase Genetic Counseling for Women with Ovarian Cancer and Their Families

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## 1. INTRODUCTION:

Ovarian cancer represents one of the most common hereditary malignancies. Genes responsible for the development of ovarian cancer have been identified and genetic testing is commercially available. Current guidelines published by the National Comprehensive Cancer Network and the Society of Gynecologic Oncology recommend that all women with invasive ovarian, fallopian tube, or primary peritoneal cancers receive further genetic risk evaluation by a genetic counselor. While hereditary risk assessment and genetic testing may have complex medical and psychological implications for patients, risk identification enables physicians to provide cost-effective tailored screening and prevention options. However, physicians continue to under-refer and women under-use genetic services. This innovative project seeks to harness mobile phone technology as a means to take preventive health care to a new level among ovarian cancer survivors. Using the Fogg Behavioral Model, developed from the concept of persuasive technology, this study proposes to develop the Mobile Application for Genetic Information on Cancer (mAGIC) intervention to motivate ovarian cancer survivors to undergo genetic counseling. The overall study objective is to develop and assess the feasibility and effectiveness of a theory-based intervention aimed to encourage ovarian cancer survivors to receive genetic counseling.

## 2. KEYWORDS:

Ovarian cancer, genetic counseling, BRCA1, BRCA2, mobile application, health technology

## 3. ACCOMPLISHMENTS:

- What were the major goals of the project?

| Specific Aim 1: Develop a tailored intervention designed to increase uptake of genetic counseling services.   | Target Comp Date | Actual Comp Date | Percent Comp |
|---|------------------|------------------|--------------|
| <b>Major Task 1:</b> Receive local IRB and DoD HRPO administrative review and approval for use of human subjects in protocol.   |                  |                  |              |
| Subtask 1a: Submission of protocol and IRB applications to University of Minnesota Cancer Center Protocol Review Committee and IRB for Aim 1.<br><i>Milestone: Protocol approved IRB approval granted</i> | 06/2014          | 08/2014          | 100          |
| Subtask 1b: Submission of the institution's IRB approval and related material for DoD's HRPO approval for Aim 1<br><i>Milestone: Receive HRPO approval</i>  | 06/2014          | 08/2014          | 100          |
| Subtask 1c: Submission of protocol and IRB applications to University of Minnesota Cancer Center Protocol Review Committee and IRB for Aim 2.<br><i>Milestone: Protocol approved IRB approval granted</i> | 11/2014          |                  | 50           |
| Subtask 1d: Submission of the institution's IRB approval and related material for DoD's HRPO approval for Aim 2<br><i>Milestone: Receive HRPO approval</i>  | 02/2015          |                  | 0            |
| <b>Major Task 2:</b> Assemble Community Advisory Board to inform intervention content.  |                  |                  |              |
| Subtask 1: Conduct quarterly meetings with Community Advisory Board<br><i>Milestone: Summary of quarterly meetings</i>  | 05/2016          |                  | 50           |



|   |         |         |     |
|---|---------|---------|-----|
| <b>Major Task 3: Conduct focus groups.</b>  |         |         |     |
| Subtask 3a: Recruit women for 3 focus groups from the University of Minnesota Gynecologic Cancer Clinic.<br><i>Milestone: Schedule participants.</i>  | 06/2014 | 11/2014 | 100 |
| Subtask 3a: Conduct focus groups among women with ovarian cancer to identify current knowledge of hereditary cancer risk, barriers to genetic counseling, and current mobile phone text and picture message habits.<br><i>Milestone: Complete transcripts and summary report.</i> | 08/2014 | 12/2014 | 100 |
| <b>Major Task 4: Develop the content and technical aspects of the intervention.</b>   |         |         |     |
| Subtask 4a: Preliminary design meeting<br><i>Milestone: Finalize length of intervention and plan for content creation.</i>  | 09/2014 | 01/2015 | 100 |
| Subtask 4b: Video creation – Consultant<br><i>Milestone: Creation of 5-7 video clips.</i>   | 11/2014 |         | 25  |
| Subtask 4c: Project Brochure and Emoticon Development – Graphic Designer<br><i>Milestone: Creation of usual care brochure, logo, and other graphics for intervention.</i>   | 11/2014 |         | 50  |
| Subtask 4d. Finalize message content.<br><i>Milestone: Library of intervention content, focusing on barriers, motivators and triggers for participating in genetic counseling.</i>  | 01/2015 |         | 75  |
| Subtask 4e. Technology Development<br><i>Milestone: Develop mobile application.</i>   | 02/2015 |         | 0   |
| <b>Major Task 5: Perform usability testing of the first prototype, refine and finalize for testing</b>  |         |         |     |
| Subtask 5a: Usability Testing<br><i>Milestone: Report of technical and usability concerns among five women with ovarian cancer and five providers who tested the prototype system.</i>  | 03/2015 |         | 0   |
| Subtask 5b: Refinement and finalization<br><i>Milestone: Refined prototype application ready for evaluation.</i>  | 05/2015 |         | 0   |
| <b>Specific Aim 2: Test the effectiveness of the intervention compared to usual care.</b>   |         |         |     |
| <b>Major Task 6: Conduct a randomized controlled trial of the intervention that focuses on assessing uptake of genetic counseling services.</b>   |         |         |     |
| Subtask 6a: Recruitment<br><i>Milestone: Enrollment of 104 consenting patients</i>  | 02/2016 |         | 0   |
| Subtask 6b: Data Collection<br><i>Milestone: Timely completion and data entry of baseline, 2 week, and 3-month post baseline surveys for all participants.</i>  | 05/2016 |         | 0   |
| Subtask 6c: Data Analysis<br><i>Milestones: Complete data analysis and testing of hypotheses.</i>   | 05/2016 |         | 0   |
| Subtask 6d: Dissemination of Results.<br><i>Milestone: Final report, Publication submission</i>   | 05/2016 |         | 0   |

- **What was accomplished under these goals?**

**Task 1: Receive local IRB and DoD HRPO administrative review and approval for use of human subjects in protocol.**

We have written a study protocol which was approved by the University of Minnesota Cancer Protocol Review Committee April 2014. The IRB and DoD HRPO have approved the human subjects components for Task 3 (focus groups) in August 2014.

**Task 2: Assemble Community Advisory Board to inform intervention content.**

We assembled a Community Advisory Board (CAB) of 5 members in addition to the study team. These include Dr. Deanna Teoh (gynecologic oncologist), Dr. Anne Blaes (oncologist with special interest in survivorship and screening), Dona Maki (oncology nurse), and two ovarian cancer survivors, Shannon Montague and Amy Herbst. They have all agreed to meet approximately quarterly and provide input regarding the scope and direction of the study. As planned, we held four CAB meetings during this reporting period.

*Meeting 1- June 24, 2014*

The purpose of this meeting was to introduce the CAB members and study team along with provide an outline of the proposed research. Discussions focused around the need for such an intervention and what expertise each CAB member brings. Slides presented at this CAB meeting are presented in Appendix A.

*Meeting 2 – November 4, 2014*

Following an update on study progress and timeline, the primary goal of this meeting was to present the preliminary findings from the focus groups (described in detail in Task 3 below). In addition, all CAB members reviewed a similar intervention created by Co-PI (H. Lee) and provided feedback on their experience. Finally we focused on a discussion of the timing and length of the intervention. It was the consensus of the CAB to limit the intervention to 7 days with 10-15 messages per day. They were enthusiastic about the inclusion of short video clips each day as well to reiterate important information. Slides presented at this CAB meeting are presented in Appendix B.

*Meeting 3- February 2, 2015*

During this CAB meeting we provided an update on study progress as well as disseminated and discussed the intervention outline. Attendees evaluated mockup of Day 1 and provided edits and design suggestions. Materials provided are presented in Appendix C.

*Meeting 4 – April 28, 2015*

This meeting included an update on study progress and a focused discussion of the Day 1 materials for the intervention and review of daily topics for the remaining days. Materials provided are presented in Appendix D.

**Task 3: Conduct focus groups.**

A series of focus groups with ovarian cancer survivors were conducted to inform the design and content of the proposed mobile intervention. These included women who have not previously attended genetic counseling and those who had attended genetic counseling.

*Study Participants and Recruitment*

We enrolled 14 women with a diagnosis of epithelial ovarian, primary peritoneal or fallopian tube cancer; 7 who have previously received genetic counseling, 4 who were referred and were unaware of purpose, and 3 who have been referred but actively declined genetic counseling. These women were recruited from the Gynecologic Cancer Clinic at the University of Minnesota-Fairview Medical Center and a local non-profit organization (Minnesota Ovarian Cancer Alliance). Eligibility criteria included: >18 years old, ability to read and write in English, voluntary written informed consent before study entry, and no known major psychiatric or neurological diagnosis. Eligible participants were approached in clinic or responded to an

email advertisement within the Minnesota Ovarian Cancer Alliance newsletter. Subjects were then called to see if they were willing to participate and to schedule participation in a focus group. A reminder letter was sent to those who scheduled, including a consent form for them to review prior to arrival.

### *Focus Groups*

Groups were conducted separately for the three populations described above; due to scheduling conflicts those who were referred and unaware of purpose were conducted on two occasions, resulting in four focus groups total. For reporting purposes, however, the information for these two groups was combined. The focus groups lasted 60-90 minutes and were held on the University campus. The study was approved by the University of Minnesota Institutional Review Board and DoD HRPO and participants provided informed consent at the start of the discussion. Each session was digitally audio-recorded and participants received \$50 for their participation. Each group had the same moderator (Niendorf) and co-moderator (Isaksson Vogel) and followed a question guide approved by all investigators (Appendix E). Topics included understanding of genetic counseling, perceived pros and cons, preferences for receiving health information, and familiarity with mobile phone technology. At the end of each session, the moderator summarized key points discussed during the focus group and requested feedback from the group regarding the accuracy of the summary. After each session, the moderator and co-moderator discussed their observations and impressions of the content and process of the focus group session. All recordings from the focus groups were transcribed and moderator summaries were documented (Appendix F).

### *Analysis*

Three researchers (Geller, Lee, Petzel) independently read the transcripts and agreed to broad themes based on the questions and goals of the study after the focus groups were conducted. Each researcher then conducted an analysis using descriptive coding techniques. Results were compared for consistency and thoroughness during multiple in-person discussions. The moderators provided additional feedback and the final product was a document outlining the main themes across four major categories: Barriers to Genetic Counseling, Facilitators, Topics to Include in the Intervention, and Features/Recommendations for Intervention.

### *Results*

A final compillation of the results is presented in Appendix G. Most issues paralleled those published in the literature and the anecdotal reports of the study team experts. These final themes were vetted by the CAB and this document was used to guide the content development of the intervention (Task 4).

## **Task 4: Develop the content and technical aspects of the intervention.**

Following completion of the focus group and summary of results, we began developing the intervention. This was an iterative process with continual input from all members of the research team and the CAB. During the reporting period we completed a draft of all of the messages and outlined the videos. We followed a 4-step process to develop the educational materials associated with the intervention.

### Step 1. Outline

We outlined the topics to be covered each of the 7 days and considered placement of videos.

The planned topics and videos include:

#### *Day 1: Introduction to Genetic Counseling*

- What is genetic counseling?
- Recommendations for women with ovarian cancer
- Video: Gynecologic Oncologist discussing genetic counseling

#### *Day 2: Genetic Testing*

- What is genetic testing?
- What genes are linked to ovarian cancer?
- Benefits of genetic testing
- Video: Patient discussing personal experience with genetic counseling and testing

#### *Day 3: Genetic Testing and Personal Health*

- Personal risk of another cancer
  - Video: Oncologist discussing screening and prevention strategies
- Day 4: Cancer Genetics and My Family*
- Sharing information with family
  - Video: Patient discussing personal experience, family discussion
- Day 5: Taking Care of Yourself*
- Worry and concerns about genetic counseling and/or testing
  - Video: Patients discussing support and coping strategies
- Day 6: Insurance, Costs and Logistics*
- Legal information about health insurance discrimination
  - Costs of genetic counseling and testing
  - Video: Genetic counselor discussing prep for genetic counseling appt
  - Phone number for appointment
- Day 7: Logistics and Summary*
- Summary of week intervention
  - Video: Patients providing final/motivation to pursue genetic counseling, thank you

## Step 2. Initial Message Creation

Our goal is to create a user-friendly, tailored, and interactive experience for the patients. We decided on the following structure within each day which provides consistency to improve ease of use and user experience:

- Welcome, Introduction to Topic of the Day
- 2-3 Interactive, Educational Questions
- Video
- Summary
- Link to health navigator for remaining questions or to schedule appointment

Writing of the content was divided up for each day by the study team experts as appropriate. Following this structure, study team members further outlined each day and presented it to the full study team at weekly meetings. Following agreement, study members wrote specific messages, questions/answers and summary statements to be included in the intervention and these were compiled into one document. The focus in this step was inclusion of messages thought to be important for the intervention; message length and number of messages were considerations but not minimized in this step. The final document prepared after this step is provided in Appendix H.

## Step 3. Message Refinement

Once it was felt all topics and issues were represented, the final step was further refinement and shortening of messages. The maximum length of a single text message is 160 characters and considerable time was spent on limiting text length with the goal of including the information within the 10-15 messages per day suggested by the CAB. This process will continue into the next reporting period and is expected to be complete June 2015.

## Step 4. Video Creation

A proposed list of videos for each day was further refined to a total of 8, 7 of which will be produced for this study. Each video will be 60-90 seconds long. Each has been outlined and currently scripts are being developed. Video production will be completed in the next reporting period.

## *Technical Considerations*

Design elements and graphics will be used to highlight some of the text and improve user experience. Each type of message will be designed consistently so users recognize a question, an answer, a video or a link. Users will answer questions by texting back a yes/no response and will receive tailored messages based on their answer. After patients complete each day's messages and watch the videos, they will receive a picture of a flower as an incentive. At the end of the 7 day intervention, users will have acquired seven flowers, which will confirm they have completed the study.

- **What opportunities for training and professional development has the project provided?**

*Nothing to Report.*

- **How were the results disseminated to communities of interest?**

*Nothing to Report.*

- **What do you plan to do during the next reporting period to accomplish the goals?**

The following tasks are ongoing. Task 3 has been completed.

**Task 1: Receive local IRB and DoD HRPO administrative review and approval for use of human subjects in protocol.**

The research team is finalizing the necessary documents for approval for Tasks 5 and 6. Appropriate human subjects documents for Task 5 have been submitted to the local IRB for approval and will be submitted to the DoD HRPO upon approval. We anticipate approval for Task 6 by both entities by August 2015.

**Task 2: Assemble Community Advisory Board to inform intervention content.**

We plan to convene another four Community Advisory Boards meetings during the next reporting period as we finalize the intervention (Task 4), perform usability testing (Task 5), and conduct the randomized controlled trial (Task 6).

**Task 4: Develop the content and technical aspects of the intervention.**

As described above, further refinement and shortening of the messages and production of the videos remain for the next reporting period. We have been in contact with our technology partner/developer MemoText and will begin weekly conference calls June 2015. We anticipate a draft of the messages by June 2015 to be reviewed by potential participants in Task 5 and then submitted to developers July 2015. Videos will be produced July 2015 and edited and ready for inclusion in the intervention by August 2015. The prototype of the intervention will be completed by September 2015 for usability testing (Task 5) and final version ready for the trial October 2015 (Task 6).

**Task 5: Perform usability testing of the first prototype, refine and finalize for testing.**

*Study Design:*

Usability testing of the intervention will be conducted in two phases, 1) testing of developed materials in print form and 2) testing of the mobile intervention prototype. This will provide crucial information that will be used to determine the final display and content of the tailored messages. In addition, usability testing will be performed to achieve system refinement and improvement. Participants, including both women with ovarian cancer and providers, will be asked to review the content and perform a think-aloud protocol, during which they voice their intentions and thought processes during a 60-90 minute individual meeting with a study investigator (Niendorf). This information will then be shared with the team for final refinement and development.

*Recruitment:*

Participants from the focus groups will be re-contacted by phone to determine their interest in participating in these next steps of intervention development. Providers, including physicians and nurses will be approached by the PI (Geller) to ascertain interest in participation. All participants will be asked to provide written consent before starting any study activities. Each participant will receive a \$50 gift card for their time.

#### *Study Procedures:*

Phase 1: Testing of printed materials. We will recruit 2-3 women with ovarian cancer and 1-2 providers to review the mAGIC intervention printed materials prior to sending them to the developer. Users will review the intervention in print form and provide initial feedback.

Phase 2: Testing of intervention prototype. Once a prototype has been developed, we will recruit 2-3 women with ovarian cancer and 1-2 providers to review the mAGIC intervention on their mobile phone. They will review the text messages and videos for each day and asked to provide feedback on the content and delivery each day. The information collected in Phase 2 will be compiled and used to make any final adjustments to the intervention before proceeding with the RCT.

Phase 1 of usability testing will be completed June 2015 and Phase 2 will be completed September 2015.

#### **Task 6: Test the effectiveness of the intervention compared to usual care.**

We will test the effectiveness of the mAGIC intervention in improving uptake of genetic counseling services among women with ovarian cancer as follows:

##### *Study Design:*

We propose a randomized controlled trial of the intervention among women with ovarian cancer who have not seen a genetic counselor with 1:1 randomization for intervention and control groups. While we anticipate overall satisfaction with the intervention, we acknowledge this is a sensitive time and topic for participants and therefore have included participants assigned to usual care as the primary comparison group. All participants will be asked to complete a baseline paper survey, brief phone interview with the patient health navigator following the intervention period (1 week), and 3 month follow-up mailed paper survey.

##### *Study Population:*

We will enroll 104 women with a diagnosis of epithelial ovarian, primary peritoneal or fallopian tube cancer, who have not previously received genetic counseling related to cancer, from the Gynecologic Cancer Clinic at the University of Minnesota-Fairview Medical Center and Fairview Maple Grove Medical Center.

##### Inclusion criteria:

- Woman diagnosed with ovarian, primary peritoneal or fallopian tube cancer
- 18 years old or older
- At least a fifth grade education
- Able to read and write in English
- Voluntary written informed consent before study entry, with the understanding that consent may be withdrawn by the subject at any time without prejudice to future medical care.

##### Exclusion criteria:

- Previous genetic counseling related to their ovarian cancer diagnosis or known cancer mutation
- Known major psychiatric or neurological diagnosis

Participants will not be required to have an appropriate mobile device as they may be supplied with one for the intervention period.

##### *Recruitment:*

Recruitment will be performed by the study coordinator and PI (Geller) by reviewing patients attending clinic with an appointment. Eligible patients will be approached by the study coordinator and provided information about the study and ask their willingness to participate.



#### *Study Procedures:*

A participant that is consented in the clinic will be immediately registered into the study by the study coordinator. This information includes their first and last name, birthdate, and phone number. Participants will complete the consent and HIPAA medical release forms and baseline survey prior to randomization. Participants will be randomized using a list created by the statistician.

All women will receive a pamphlet on hereditary cancer risk and genetic counseling at the time study entry, per usual care and will be provided with information on local genetic counseling options. Individuals whose genetic counseling is not covered by their health insurance or do not have health insurance may request the study cover their genetic counseling costs. All participants will also receive a \$20 gift card at the start of the study for study participation and will receive the final \$20 gift card after completing the follow-up survey at 3 months.

Those randomized to the intervention group will be provided an instruction sheet and trained on its use with either their own smartphone or, if needed, a smartphone we will provide to them for the duration of the study intervention. During this session, the application will be installed for them and they will be taught how to open the application, enter their username/password, reply to questions, view videos and links to websites. The participants can contact the patient health navigator with questions or trouble with usage of the smartphone during the study. Those assigned to the intervention group will begin receiving messages on the day of their choosing, within one week of study entry.

Regardless of randomization assignment, participants will receive a phone call from the patient health navigator one week following enrollment to determine their intentions, self-efficacy, and communication with family regarding seeking genetic counseling. Three months following study entry, all participants will be asked to complete a follow-up survey, either in the clinic or returned by mail.

#### *Statistical Methods:*

Hypothesis 1 (Primary Outcome). Participants randomized to the mAGIC intervention will have greater uptake of genetic counseling services compared to those randomized to the control group.

Hypothesis 2. Participants randomized to the mAGIC intervention group will have greater intent and self-efficacy in making a genetic counseling appointment and in communicating with their family about hereditary cancer risk than those randomized to the control group.

Hypothesis 3. Participants randomized to the mAGIC intervention group will have increased knowledge of ovarian cancer and hereditary cancer risks than those randomized to the control group.

Hypothesis 4. Participants randomized to the mAGIC intervention group will report high acceptance of and satisfaction with the intervention.

Patient demographics and clinical information will be descriptively summarized. To address Hypothesis 1, the proportion of women in each group (intervention vs. control) who attended genetic counseling within 3 months of study entry will be compared using a Fisher's Exact test. Analyses will be performed using intention-to-treat methods, though our goal is that all women assigned to the intervention group receive the intervention. For Hypotheses 2 to 4, mean change in score and standard deviations will be calculated by treatment and control group and compared using t-tests as appropriate. P-values < 0.05 will be considered statistically significant.

#### *Anticipated Timeline and Manuscript Preparation*

Recruitment for the randomized controlled trial will begin October 2015 and the study is expected to stop enrollment April 2015 with follow-up completed by July 2015. Manuscript preparation and submission will follow.

## **4. IMPACT:**

- **What was the impact on the development of the principal discipline(s) of the project?**

Identification of a hereditary syndrome usually triggers the screening for cancers at an earlier age and at more frequent intervals than for persons in the general population, allowing for detection of cancers at earlier

stages.(1, 2) In addition to earlier surveillance, different surgical and treatment options, including prophylactic surgeries of at-risk organs, also may be indicated to decrease the chances a cancer will develop.(2-4) In addition, evolving discoveries related to prognosis and treatment of the ovarian cancer patient with *hereditary mutations* highlights the necessity of genetic testing in the care of these patients. Despite the above data, recent studies continue to find that referring providers are not able to consistently recognize appropriate referral indications for hereditary breast and ovarian cancer risk assessment and genetic counseling.(5-8) There is evidence that the classical, provider-centric “top down” approach to identifying and triaging individuals at high risk for hereditary ovarian cancer has failed. In this pilot project, we propose a “bottom-up” alternative strategy of educating ovarian cancer survivors about the recommendations for genetic counseling and possible genetic testing.

Even with many consensus guidelines recommending the referral of all invasive ovarian, fallopian tube and primary peritoneal cancer patients to genetic counseling and, some insurers requiring genetic counseling before genetic testing, not all patients receive the recommended genetic counseling.(9, 10) For this reason, it is imperative that both providers and patients understand the meaning and value of genetic counseling to ensure compliance with recommended genetic counseling. This mobile application provides a new tool for disseminating this needed information about genetic counseling directly to the relevant patient population. If accepted into practice, the results from this mobile application can be tracked for evidence of an increase in the uptake of genetic counseling as well as adherence to recommendations for identification and referral of at-risk patients.

- **What was the impact on other disciplines?**

This evidence-based and effective *mAGIC* intervention could be adapted to promote high quality survivorship care by targeting any number of other positive health care behaviors or screening programs and would have a broad impact on the dissemination of health information to individuals, families, and health providers. Identification of a genetic mutation within a family impacts the cancer screening in as-yet unaffected family members within the primary care population - either through an increase or decrease in screening/prevention measures dependent upon the results of genetic counseling and testing.

- **What was the impact on technology transfer?**

*Nothing to report.*

- **What was the impact on society beyond science and technology?**

The *mAGIC* intervention will potentially increase the uptake of genetic counseling and the identification of women with ovarian cancer who have a hereditary syndrome. Genetic counseling and testing would allow women with epithelial ovarian cancer and their families to receive information about prophylactic surgeries and screening which could reduce the risk of dying from a subsequent breast cancer by 90% and family members dying from ovarian cancer by 95%.(11)

Given the current incidence of ovarian cancer in the United States, hereditary cancer syndromes will lead to approximately 2200 new cases of ovarian cancer in 2013. For families with high risk hereditary cancer syndromes, there are estimated to be *8-10 first degree relatives at risk* which translates into 17,600-22,000 people who could be directly affected with knowledge of the presence of a hereditary gene mutation. Cancer genetic counseling and testing services have been shown to increase protective behaviors such as surveillance and prophylactic surgical interventions, which in turn decrease cancer morbidity and mortality.(2, 12)

Cancer genetic counseling and testing became available approximately 25 years ago. At that time, uncertainty regarding the usefulness of knowing one’s genetic status as well as potential risks of genetic discrimination created barriers to receipt of genetic counseling and testing. Although the benefits of genetic counseling and testing are now well established, societal beliefs are slower to change. Myths surrounding the risks of genetic information still continue to be cited as barriers to receipt of genetic counseling and testing. This new tool will provide a venue for educating patients about the benefits of genetic counseling while also addressing remaining concerns. If successful, the similar tools may be used for education on other topics.

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## **5. CHANGES/PROBLEMS:**

*Nothing to Report.*

## 6. PRODUCTS:

- **Publications, conference papers, and presentations**

*Poster to be Presented June 2015*

Petzel S, Lee H, Lee H, Niendorf K, Isaksson Vogel R, Geller MA. “Developing a mobile application to increase genetic counseling for women with ovarian cancer.” World Congress of Psycho-Oncology, Washington D.C.

- **Website(s) or other Internet site(s)**

*Nothing to Report.*

- **Technologies or techniques**

*Nothing to Report.*

- **Inventions, patent applications, and/or licenses**

*Nothing to Report.*

- **Other Products**

*Nothing to Report.*

## 7. PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS

- **What individuals have worked on the project?**

|  |  |
|--|--|
| Name:                                  | <i>Melissa A. Geller</i>   |
| Project Role:                          | <i>Principal Investigator</i>  |
| Researcher Identifier (e.g. ORCID ID): |  |
| Nearest person month worked:           | <i>1</i>   |
| Contribution to Project:               | <i>Dr. Geller provided leadership and her clinical expertise for intervention development.</i> |

|  |  |
|--|--|
| Name:                                  | <i>Hee Yun Lee</i>   |
| Project Role:                          | <i>Principal Investigator</i>  |
| Researcher Identifier (e.g. ORCID ID): |  |
| Nearest person month worked:           | <i>1</i>   |
| Contribution to Project:               | <i>Dr. Lee provided leadership and provided expertise in intervention development.</i> |

|  |   |
|--|---|
| Name:                                  | <i>Kristin Niendorf</i>   |
| Project Role:                          | <i>Co-Investigator</i>  |
| Researcher Identifier (e.g. ORCID ID): |   |
| Nearest person month worked:           | <i>1</i>  |
| Contribution to Project:               | <i>Ms. Niendorf conducted the focus groups and provided expertise in intervention development as genetic counselor.</i> |

|  |   |
|--|---|
| Name:                                  | <i>Rachel Isaksson Vogel</i>  |
| Project Role:                          | <i>Statistician</i>   |
| Researcher Identifier (e.g. ORCID ID): |   |
| Nearest person month worked:           | <i>1</i>  |
| Contribution to Project:               | <i>Ms. Vogel analyzed focus group data and provided guidance in development of intervention and study design.</i> |

- **Has there been a change in the active other support of the PD/PI(s) or senior/key personnel since the last reporting period?**

Melissa Geller

***New Active Support***

(Geller, M)

01/01/2015-12/31/2018 1.8 calendar months

American Cancer Society

**Natural Killer Cell Immunotherapy for Ovarian Cancer**

*Major Goals:* We are developing an anti-mesothelin chimeric antigen receptor (CAR) in iPSCs to produce a targeted NK cell population effective against ovarian cancer, where 70% of tumors express mesothelin. Our goal is for CAR-expressing NK cells to be used as a readily available, "off-the-shelf" product for anti-tumor immunotherapy.

*Specific Aims:* 1) Express an anti-mesothelin chimeric antigen receptor (CAR) in human induced pluripotent stem cells (iPSCs) to create targeted NK cells with increased ability to kill human ovarian cancer cells. 2) Evaluate *in vivo* anti-ovarian cancer activity of NK cells derived from human iPSCs expressing anti-mesothelin chimeric receptors.

*Role:* Principal Investigator

*Agency Contact:* The American Cancer Society, Extramural Grants Department 250 Williams Street NW, 6th Floor Atlanta, GA 30303

(Starr T, Bazzaro M, Geller M)

08/01/13-07/31/15

0.12 calendar months

Masonic Cancer Center, University of Minnesota

**Personalized Mouse Models of Chemotherapy Resistance in Ovarian Cancer**

*Major Goals:* To identify molecular signatures that predict response to platinum/taxane therapy.

*Specific Aim:* Identify molecular signatures that predict response to platinum/taxane therapy. Sub aim A:

Establish PDX models from ten patients with high-grade serous ovarian cancer. Sub aim B: Treat PDX models with carboplatin and paclitaxel and determine if the tumors are refractory, resistant or sensitive. Sub aim C:

Identify gene expression patterns that correlate with tumor subsets that are refractory, resistant, or sensitive to platinum/taxane chemotherapy.

*Role:* Co-Principal Investigator

*Agency Contact:* Masonic Cancer Center, University of Minnesota, Dinnaken Office Building, Suite 310, 925 Delaware Street SE, Minneapolis, MN 55414. Phone: 612-624-0650

(Geller, M)

05/01/14-04/30/16

0.12 calendar months

Minnesota Ovarian Cancer Alliance

**Indoleamine-2,3-dioxygenase (IDO) Inhibition with INCB02**

*Major Goals:* 1) To determine the maximum tolerated dose (MTD) of INCB024360 when administered with intraperitoneal haploidentical donor NK Cells/IL-2 after nonmyeloablative cyclophosphamide/fludarabine (Cy/Flu) preparative regimen in patients with recurrent ovarian, fallopian tube, and primary peritoneal cancer. 2) To evaluate peripheral blood and peritoneal washing immune cell IDO inhibition, markers of inflammation, and immune modulation and to correlate these parameters with disease response.

*Role:* Principal Investigator

*Agency Contact:* Kathleen Gavin, Executive Director, Minnesota Ovarian Cancer Alliance, 4604 Chicago Avenue South, Minneapolis, MN 55407. Phone: 612/822-0500

(Kaufman DS, Haluska P)

02/01/14-01/31/16

0.60 calendar months MN

Partnership for Biotechnology and Medical Genomics

**Genomic Approach for Targeted Immunotherapy Against Ovarian Cancer**

*Major Goals:* The goal of this study is to use induced pluripotent stem cells (iPSCs) to produce NK cells engineered to express anti-ovarian (antigen = mesothelin) cancer chimeric antigen receptors (CARs) or bispecific killer cell immune engagers (BiKEs).

*Specific Aims:* 1) Evaluate response of primary ovarian cancer cells grown in immunodeficient mice (Avatar mice) to targeted cellular immune therapy. 2) Characterize genomic profile of tumors with best and worst response to immune therapies.

*Role:* Co-Investigator

*Agency Contact:* Bart Bevins, Suite 200, 332 Minnesota Street, St. Paul, MN 55101-1350. Phone: 651-282-5014

(Geller, M)

08/01/13-08/30/19

0.12 calendar months

Tesaro, Inc.

**A Phase 3 Randomized Double-blind Trial of Maintenance with Niraparib versus Placebo in Patients with Platinum Sensitive Ovarian Cancer**

*Major Goal:* Phase 3 clinical trial to determine the effect of Niraparib versus placebo in patients with platinum sensitive ovarian cancer.

*Role:* Principal Investigator

*Agency Contact:* Richard Rogers, CFO, Tesaro, Inc, 1000 Winter Street, Suite #3300, Waltham, MA 02451

**Grants Closed**

(Skubitz, A)

07/01/2013-06/30/2014

0.12 calendar months

Minnesota Ovarian Cancer Alliance (MOCA)

**Identification and Validation of Ovarian Cancer Protein Biomarkers in Routine Pap Tests**

*Major Goals:* The major goals of this study are to validate some of the prognostic biomarkers that we had discovered to see whether they would be present in additional cohorts of patients.

*Specific Aims:* 1) Identify proteins present in the Pap test fixative that are unique and/or differentially expressed in samples from ovarian cancer patients compared to healthy women; 2) Identify proteins present in the cervical swabs that are unique and/or differentially expressed in samples from ovarian cancer patients compared to healthy women; 3) Validate the presence of specific ovarian cancer proteins in Pap test samples using a second cohort of patients.

*Role:* Co-Investigator

*Agency Contact:* Kathleen Gavin, Executive Director, Minnesota Ovarian Cancer Alliance, 4604 Chicago Avenue South, Minneapolis, MN 55407. Phone: 612/822-0500



(Geller, M) 01/01/2013-05/31/2014 0.12 calendar months  
Masonic Cancer Center, University of Minnesota  
**Website-based Hereditary Cancer Risk Assessment for Ovarian Cancer Patients**  
*Major Goals:* To implement a system to automate and increase patient and provider awareness of hereditary cancer risk using the “Together Website”.  
*Specific Aims:* 1) Develop the programming necessary for the “Together website to serve as both the patient interface and database for hereditary cancer risk assessment process; 2) Validate the hereditary cancer risk assessment algorithm using ovarian cancer cases from the Bernstein Registry; 3) Conduct usability testing of the interface among women diagnosed with ovarian cancer.  
*Role:* Principal Investigator  
*Agency Contact:* Masonic Cancer Center, University of Minnesota, Dinnaken Office Building, Suite 310, 925 Delaware Street SE, Minneapolis, MN 55414. Phone: 612-624-0650

(Geller, M) 09/01/2012-08/31/2014 0.12 calendar months  
Office of Discovery and Translation, U of Minnesota  
**Transposon-mediated Targeting of Natural Killer Cells for Ovarian Cancer Immunotherapy**  
*Major Goal:* To determine the feasibility of using NK cells targeted to ovarian cancer as a strategy to maximize the anti-tumor effects of NK cells. This study will provide key preclinical data needed to advance this promising targeted NK cell-based therapy into clinical trials for ovarian cancer patients not responding to traditional therapeutic regimens.  
*Specific Aims:* 1) To derive anti-mesothelin CAR expressing NK cells from human iPSCs. 2) To demonstrate increased anti-ovarian cancer activity of anti-mesothelin CAR expressing iPSC-derived NK cells. 3) *In vivo* testing of iPSC-derived NK cells expressing the anti-mesothelin CAR.  
*Role:* Principal Investigator  
*Agency Contact:* Clinical and Translational Science Institute, University of Minnesota 717 Delaware Street S.E., Minneapolis, MN 55414. Phone: 612-625-2874

(Geller, M) 07/01/2012-06/30/2014 0.12 calendar months  
Minnesota Ovarian Cancer Alliance  
**Minnelide: A Novel Therapeutic Agent for Ovarian Cancer**  
*Major Goal:* To determine synergy between Minnelide and carboplatin/paclitaxel in ovarian cancer cell lines, and to evaluate the efficacy of Minnelide in multiple animal models of ovarian cancer.  
*Specific Aims:* 1) To determine synergy between Minnelide and carboplatin/paclitaxel in ovarian cancer cell lines. To critically evaluate the effect of Minnelide on paclitaxel-resistant and platinum-resistant ovarian cancer cell lines. 2) To evaluate the efficacy of Minnelide in multiple animal models of ovarian cancer, including orthotopic models using established ovarian cancer cell lines and a human ovarian cancer xenograft model.  
*Role:* Principal Investigator  
*Program Official:* Kathleen Gavin, Executive Director, Minnesota Ovarian Cancer Alliance 4604 Chicago Avenue South, Minneapolis, MN 55407. Phone: 612/822-0500

(Geller, M) 11/01/2011-10/31/2014 0.12 calendar months  
Minnesota Ovarian Cancer Alliance  
**Lymphodepleting Chemotherapy and T-Cell Suppression Followed by Allogeneic Natural Killer Cells and Interleukin-2 in Patients with Recurrent Ovarian Cancer**  
*Major Goal:* To test the central hypothesis that successful NK cell therapy will require suppression of the T-cell compartment to allow NK cells to persist, expand, and function in vivo to exhibit a therapeutic response in women with advanced ovarian cancer.  
*Specific Aims:* 1) To optimize a clinical platform of lymphodepleting chemotherapy and T-cell suppression to promote the persistence, function, and expansion of allogeneic NK cells; 2) To determine the clinical efficacy of *in vivo* expanded haploidentical allogeneic NK Cell therapy following lymphodepleting chemotherapy and T-cell suppression in patients with recurrent ovarian cancer in a Phase II clinical trial.  
*Role:* Principal Investigator  
*Agency Contact:* Kathleen Gavin, Executive Director, Minnesota Ovarian Cancer Alliance 4604 Chicago Avenue South, Minneapolis, MN 55407. Phone: 612/822-0500

Hee Yun Lee

***New Active Support***

(Lee, HY, Height W, Kayama M)

1/01/2014-12/31/2015 0.60 calendar months

Spencer Foundation

**Disability, stigma and school: Lessons from Japanese, South Korean, and Taiwanese educators**

*Major Goal:* This study aims to explore stigma attached to disability among elementary school students in Japan, South Korea, and Taiwan.

*Role:* Co-Principal Investigator

*Agency Contact:* Amy K. Levine, Research Development Coordinator University of Minnesota, College of Education and Human Development 169 Peters Hall, 1404 Gortner Avenue St. Paul, MN 55108; ALevine@umn.edu

(Lee, HY)

1/01/2015-12/31/2018 3.00 calendar

months Minnesota Agricultural Experiment Station (MIN-55-017)

**Asian American Immigrant Parents' Health Literacy and its Link to Children's Depressive Symptoms**

*Major Goal:* This study aims to investigate how parental health literacy impacts on children's depressive symptoms in Asian American immigrant communities.

*Role:* Principal Investigator

*Agency Contact:* Amy K. Levine, Research Development Coordinator University of Minnesota, College of Education and Human Development 169 Peters Hall, 1404 Gortner Avenue St. Paul, MN 55108; ALevine@umn.edu

(Lee, HY)

1/01/2015-12/31/2015 0.36 calendar months

University of Minnesota

**Asian American Immigrant Parents' Health Literacy and its Association with Children's Mental Health Disparities**

*Major Goal:* This study aims to explore the relationship between parents; health literacy and children's mental health disparities using population-based health data.

*Role:* Principal Investigator

*Agency Contact:* Amy K. Levine, Research Development Coordinator University of Minnesota, College of Education and Human Development 169 Peters Hall, 1404 Gortner Avenue St. Paul, MN 55108; ALevine@umn.edu

***Grants Closed***

(Lee, HY)

01/01/2014-12/31/2014 0.60 calendar months

Sanford Research Foundation

**Determinants of Care & Life Quality in American Indian Women with Cervical Cancer**

*Major Goals:* To investigate the determinants of care & life quality in American Indian women with cervical cancer.

*Specific Aims:* 1) To assess subjective experience of American Indian women diagnosed with cervical cancer within the past three years and its meaning in the lives of American Indian women and their families and tribes. 2) To uncover the role, if any, that religion/spirituality and social supports play in American Indian cancer coping strategies. 3) To examine the prevalence of depression, the level of quality of life and the related social determinants among American Indian women with cervical cancer.

*Role:* Consultant

*Agency Contact:* Tabatha Lemke, Grant Coordinator Sanford Research, 2301 E. 60th Street North | Sioux Falls, SD 57104-0569, researchgrants@SanfordHealth.org

Kristin Niendorf

**Grants Closed**

(Geller, M)

01/01/2013-05/31/2014 0.12 calendar months

Masonic Cancer Center, University of Minnesota

**Website-based Hereditary Cancer Risk Assessment for Ovarian Cancer Patients**

*Major Goals:* To implement a system to automate and increase patient and provider awareness of hereditary cancer risk using the “Together Website”.

*Specific Aims:* 1) Develop the programming necessary for the “Together website to serve as both the patient interface and database for hereditary cancer risk assessment process; 2) Validate the hereditary cancer risk assessment algorithm using ovarian cancer cases from the Bernstein Registry; 3) Conduct usability testing of the interface among women diagnosed with ovarian cancer.

*Role:* Co-Investigator

*Agency Contact:* Masonic Cancer Center, University of Minnesota, Dinnaken Office Building, Suite 310, 925 Delaware Street SE, Minneapolis, MN 55414. Phone: 612-624-0650

▪ **What other organizations were involved as partners?**

*Not applicable for reporting period.*

**8. SPECIAL REPORTING REQUIREMENTS**

*Not applicable.*

**9. APPENDICES:**

- A. Community Advisory Board Meeting 1 Presentation
- B. Community Advisory Board Meeting 2 Presentation
- C. Community Advisory Board Meeting 3 Handout
- D. Community Advisory Board Meeting 4 Handout
- E. Focus Group Moderator Guides
- F. Focus Group Moderator Summaries
- G. Focus Group Results of Thematic Analysis
- H. Preliminary Intervention Messaging



MOBILE APPLICATION FOR GENETIC INFORMATION ON CANCER



Melissa Geller, MD, Co-PI

Hee Yun Lee, PhD, Co-PI

Team: Kristin Baker Niendorf, Rachel Isaksson Vogel, Matt Gerber, Sue Petzel. Heewon Lee



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# mAGIC: Mobile Application for Genetic Information on Cancer

- *DOD Funding 2014-2016*
  - *Melissa Geller, MD and Hee Yun Lee, PhD PIs*
1. This study proposes to develop the *Mobile Application for Genetic Information on Cancer (mAGIC)* intervention to encourage ovarian cancer survivors to undergo genetic counseling.
  2. The overall study objective is to develop and test the effectiveness of a week-long mobile phone based *mAGIC* intervention aimed to persuade ovarian cancer survivors to receive genetic counseling
  3. The long-term goal is to expand this intervention to family members and individuals with other cancers.





# SGO Position Statement: Genetic Testing for Gynecologic Cancer (March 2014)

**Statement:** The Society of Gynecologic Oncology strongly **supports genetic counseling and testing for hereditary gynecologic cancers**. For patients with ovarian cancer or endometrial cancer, genetic test results may identify those women who are at increased risk for second cancers and may be important information for the prevention of cancer in their family members. Hereditary gynecologic cancers include those of the ovaries or fallopian tubes, peritoneum and uterus.

**Ovarian cancer:** Women diagnosed with epithelial ovarian, fallopian tube, and peritoneal cancers should receive genetic counseling and consider genetic testing, even in the absence of a family history of cancer.

**Endometrial cancer:** All women diagnosed with endometrial cancer should have a clinical assessment (review of personal and family history) and/or molecular assessment (tumor testing) for Lynch syndrome.





# National Comprehensive Cancer Network Practice Guidelines

- *NCCN Guidelines version 1.2014*

“Genetic counseling is highly recommended when genetic testing is offered and after results are disclosed.”

[http://www.nccn.org/professionals/physician\\_gls/pdf/genetics\\_screening.pdf](http://www.nccn.org/professionals/physician_gls/pdf/genetics_screening.pdf)



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# Traditional Model: High Risk Care

1. Provider identifies risk
2. Provider refers patient to genetic counselor
3. Genetic counselor identifies the mutation/syndromes
4. Genetic counselor sends patient back to MD for management



# Use and Referral Rates

- 20% of primary care patients have family histories placing them at high risk
- Family histories are not detailed enough to identify at-risk patients (must be 3 generation)
- Primary care providers are not comfortable (on average) with genetic risk information
- Referral rates to genetic counseling low (< 50%)
- Incomplete uptake of genetic counseling by referred patients

- Wood et al. Family Practice 2008; 25: 334–340
- Wideroff et al. J Med Genet 2005;42:749–755
- O'Neill et al. Am J Med Genet Part C 2006; 142C:221–231



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# Genetic counseling/health education studies

1. Bernstein Management Program
2. eFHQ: Electronic family history questionnaire
3. Genetic Counseling Barrier Study
4. Mammography study
5. mAGIC: Mobile Application for Genetic Information



# BERNSTEIN REGISTRY Protocol

## SCREENER

869/1992 (44% uptake), 88% eligible

## FAMILY HISTORY

500/769 (65% uptake)

## PEDIGREE GENERATED

## Genetic Counselor Risk Assessment

(Hampel et al. 2004 J Med Genet)

Genetic counseling < 10%

### HIGH

Genetic counseling referral  
and primary care provider  
discussion

332/500 (66%)

### MODERATE

Discussion with primary care  
provider

102/500 (20%)

### AVERAGE

General cancer risk

66/500 (13%)

Process well  
received

# eFamily History Questionnaire

1. Online family history data entry
2. Hereditary cancer risk assessment
3. Genetic counseling referral letter

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Driven to Discover™

Help Save, Finish Later

### Family History Questionnaire

100% complete

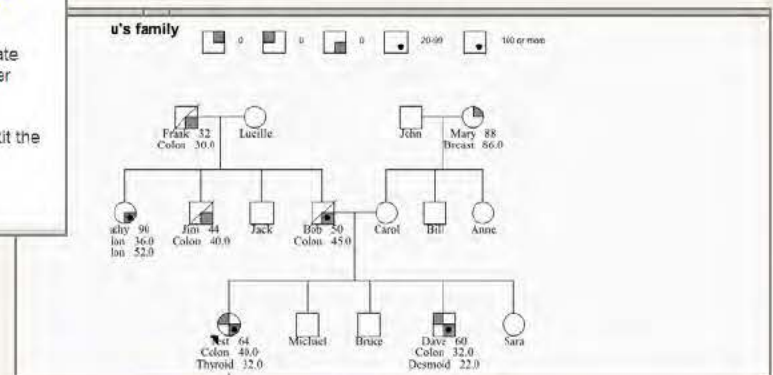
Thank you for completing the questionnaire!

This final page provides complete access to all the data you have entered thus far both about yourself and each of your relatives. To view your completed family tree or to print a copy for your records, please click the [View or Print Your Family Tree](#) button below.

If you need to edit any information about yourself or an existing family member, please choose the appropriate questionnaire page or family member below and click the green [Edit](#) button. Should you need to add another family member, please use the blue [Add Family Member](#) button at the bottom.

When you are finished with this Family History Questionnaire and are ready to complete the process and exit the application, please click the green [Save and Submit](#) button on the bottom right.

Edit My Information Welcome! [Edit](#)



Masonic Cancer center grant



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# Perceived Barriers to Genetic Counseling

1. Cost (57.3%)
2. Insurance discrimination
3. Other priorities and being overwhelmed by information

\* The lowest, at 6.5% was “family is discouraging genetic counseling”



# eFHQ: Gynecologic Cancer Clinic

- *Current Trial*

1. Usability testing (5 staff + 2 patients) – completed
2. Pilot (50 ovarian cancer patients) – ongoing ~ 12 accrued
3. Completion = August 2014





**Mobile Phone Multimedia Messaging  
Intervention for Breast Cancer  
Screening**

**PI: Hee Yun Lee, Ph.D.**


**Co-Investigators:**

**Doug Yee, M.D.**

**Rahel Ghebre, M.D.**

**Chap Le, Ph.D.**

# Introduction of mMammogram App

- 15-20 messages per day
- Send each message every 30 seconds.
- Interactive message (e.g., question) takes 60 seconds
- Takes 15-20 minutes to complete each day's program
- Collect pink ribbon ( ) which  responding to each question or quiz and provide incentive at the end of program







1:54 PM



## Messages



raise: women over aged 40  
or over need to receive a  
mammogram"

Sep 5, 2013 1:46 PM

Korean immigrant women  
have higher risk for breast  
cancer than Korean women  
who live in Korea. Guess  
how many more times  
would it be? 1) 1.5 times  
2) 2.5 times

Sep 5, 2013 1:54 PM

2

Sep 5, 2013 1:54 PM

Yes, you're right. Isn't it sad  
statistics? Let's reverse this  
trend!

Enter Message

Send

Cancer Care



## Adhoc Send Message

Participant Mgmt

History &amp; Messages

Participant Response

Participant History &amp; Msg | Adhoc Send Message

## ADHOC MESSAGE

 Indicates Mandatory Fields

Group

12 PM to 2 PM



Participant(s)

26 - 5409086508 - Minsun



Message to be sent

Did you know that cervical cancer is increasing in Korean women in their 20s? We want to change these sad statistics. This is why we are here for you!

Send





# Introduction of mMammogram App

- Used emoticons to motivate participants' involvement and raise interest

- Examples of emoticons



- Instant help is provided when clicking on phone icon.
- Health navigator will respond to the



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# Content of mMammogram App

- 7day program

| Day | Theme                                    |
|-----|--|
| 1   | Introduction to breast cancer            |
| 2   | Introduction to breast screening methods |
| 3   | “Knowledge day”                          |
| 4   | “Accessibility day”                      |
| 5   | “Culture day”                            |
| 6   | “Clinic day”                             |
| 7   | “Summary day” _ Quiz                     |

# Day1. Introduction To Breast Cancer

- Prevalence: Korean immigrant women > Korean native women
- Mortality & Testimony
  - Video with Dr. Yee “Mortality”
  - Video with Ms. Lim “testimony”
- Characteristic of breast cancer
  - A photo taken by mammogram
- Risk factors of breast cancer





# Day2. Introduction to Breast Cancer Screening Methods

- Introduction to mammograms
  - Video of mammogram
- Introduction to BSE (Breast Self-Exam) and its limitation
  - Video of BSE
- Introduction to CBE (Clinical Breast Exam) and its limitation
  - Video of CBE



## Day3. Knowledge Day

- Guideline about age for a regular mammogram
- Guideline about frequency of a regular mammogram
- Pain
  - Video with Ms. Kim's experience of pain during mammogram
- Radiation
  - Video with Dr. Rahel about the risk of harm from the radiation exposure during mammogram



## Day4. Accessibility Day

- Financial status/insurance
  - Introduction of SAGE (free breast cancer screening by the Minnesota government)
- Transportation/lack of mobility
- Language (English)
- Complexity of US health care system
- Lack of physician's encouragement





## Day5. Culture Day

- Fatalistic view
- Feeling afraid about finding out cancer
  - Chart of survivor rate by breast cancer stage
- Traditional views about Korean women's roles
- Feeling shy or embarrassed with breast (body) exposures
  - Video with Kristy, a technician of U of MN breast cancer imaging center
  - Detailed procedure of receiving a mammogram



## Day 6. Clinic Day

- ▶ Insurance information for tailoring
- ▶ Clinic information (GPS)
- ▶ Intention about a future plan

## Day 7. Summary and Quiz Day

- Provide quiz to highlight important message.
- Summarize what we have learned
- Ask intention to receive mammogram
- Wrap up the program



# Questions and Answers



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# mAGIC: Mobile Application for Genetic Information on Cancer

- *DOD Funding 2014-2016*
  - *Melissa Geller, MD and Hee Yun Lee, PhD PIs*
1. This study proposes to develop the *Mobile Application for Genetic Information on Cancer (mAGIC)* intervention to encourage ovarian cancer survivors to undergo genetic counseling.
  2. The overall study objective is to develop and test the effectiveness of a week-long mobile phone based *mAGIC* intervention aimed to persuade ovarian cancer survivors to receive genetic counseling
  3. The long-term goal is to expand this intervention to family members and individuals with other cancers.



## Aim 1

- *Develop a tailored mAGIC intervention designed to increase uptake of genetic counseling services.*

Following the FBM, this intervention will consist of three parts: (1) identifying barriers, (2) developing motivators, and (3) providing triggers to action to pursue cancer genetic counseling services.





## Aim 2

- ***Aim 2. Test the effectiveness of the mAGIC intervention compared to usual care.***

We propose to randomize women with a history of ovarian, fallopian or primary peritoneal cancer who have previously not met with a genetic counselor to either the intervention or a control group. We will test the following hypotheses:



# Hypotheses

- ***Hypothesis 1 (Primary Outcome).***

Participants randomized to the *mAGIC* intervention will have greater uptake of genetic counseling services compared to those randomized to the control group.



# Hypotheses:

- *Secondary*

**Hypothesis 2.** Participants randomized to the *mAGIC* intervention group will have greater intent to make and confidence in making a genetic counseling appointment and communicate with their family about hereditary cancer risk than those randomized to the control group.

**Hypothesis 3.** Participants randomized to the *mAGIC* intervention group will have increased knowledge of ovarian cancer and hereditary cancer risks than those randomized to the control group.

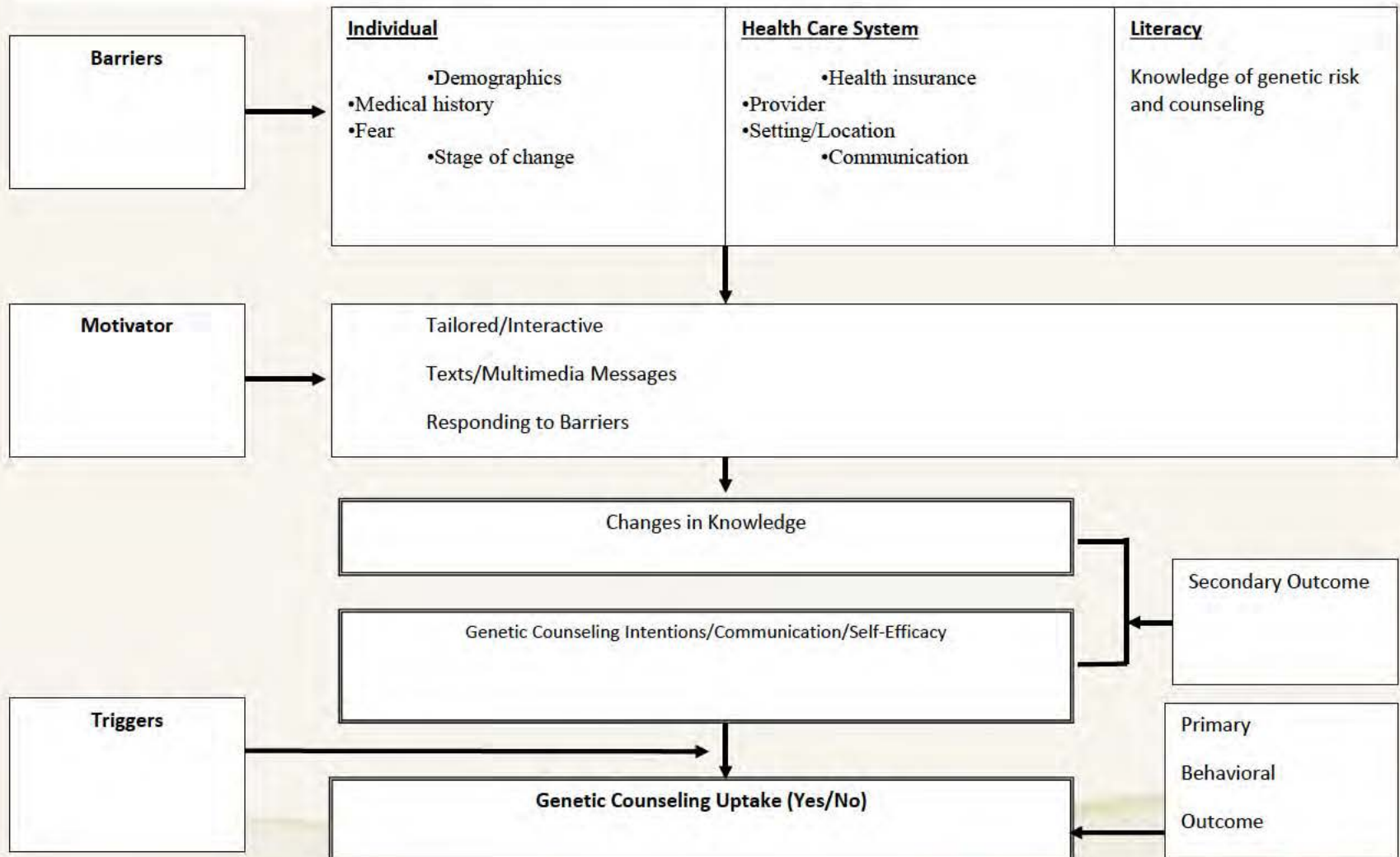
**Hypothesis 4.** Participants randomized to the *mAGIC* intervention group will report high acceptance of and satisfaction with the intervention.





# mAGIC: study design

Figure 1. Conceptual Framework of the Study



# Development

- *mAGIC Development:*

Intervention development involves *five steps*: (1) gathering a Community Advisory Board (CAB) and conducting focus groups, (2) identifying barriers and assessing mobile phone usage patterns/ preferences, (3) creating motivators, (4) tailoring message content, and (5) developing appropriate triggers.





# Community Advisory Board (CAB)

- *Total meetings < 6 times over two year*
- *5 members, \$300 compensation*
- *Contact: Kristin Niendorf: baker603@umn.edu*

## 1. Year 1: 3-5 times

- 2-3 in 6 months – Develop focus groups
- 1-2 last 6 months – Use focus data for messages

## 2. Year 2: 1-2 times – Data evaluation



## Focus groups:

- *Barriers, motivators and messages*
1. 3 groups (2 without GC and 1 with GC)
  2. Pre-meeting survey
  3. 90 min., 5-8 women – Gyn-Onc clinic
  4. Using standard moderator guide
  5. \$50 compensation,



# Study

- *Participants = 82*
1. Randomized to mAGIC vs. usual care
  2. All to receive GC information
  3. GC will be covered for those without insurance coverage
  4. \$40 compensation



# Cell phone messages

- *One week*

**Table 1. Planned Intervention Topics – General, Interactive and Tailored Information and Messages**

|                                 | Day 1                        | Day 2                                | Day 3                                     | Day 4   | Day 5  | Day 6                        | Day 7  |
|---------------------------------|------------------------------|--------------------------------------|---|---|--|------------------------------|--|
| <b><i>m</i>AGIC<br/>content</b> | Hereditary<br>cancer<br>risk | Benefits of<br>genetic<br>counseling | Cost of genetic<br>counseling/<br>testing | Insurance<br>discrimination,<br>genetic testing | Emotional<br>impact of genetic<br>counseling | Communicating<br>with family | Review quizzes<br>and making an<br>appointment |





# Study data

## • Measures

| Table 2. Study Outcome Measures                                  |  |          |        |        |
|--|--|----------|--------|--------|
| Measure  | Details  | Baseline | 2 wks. | 3 mos. |
| <b>Hypothesis 1 (Primary Outcome)</b>                            |  |          |        |        |
| Genetic Counseling Uptake  | Documented attendance of genetic counseling appointment                              | X        | X      | X      |
| <b>Hypothesis 2</b>  |  |          |        |        |
| Intention to make a Genetic Counseling Appointment <sup>37</sup> | Stage of readiness for seeking cancer genetic counseling services, based on the PAPM | X        | X      | X      |
| Self-Efficacy  | Confidence in making an appointment for genetic counseling                           | X        | X      | X      |
| Communication with Family <sup>45</sup>                          | Openness to discuss cancer risk with nuclear family                                  | X        | X      | X      |
| <b>Hypothesis 3</b>  |  |          |        |        |
| Knowledge about Hereditary Cancer <sup>46</sup>                  | Breast cancer and hereditary knowledge scale modified for ovarian cancer             | X        |        | X      |
| Risk Perception <sup>47</sup>                                    | Visual analog scale of perceived risk of hereditary cancer                           | X        |        | X      |
| <b>Hypothesis 4</b>  |  |          |        |        |
| Technology Acceptance Model (TAM) <sup>48,49</sup>               | Measure of technology acceptance, satisfaction, and usability                        |          |        | X      |
| Impact of Event (IES) <sup>50</sup>                              | Avoidance and intrusion subscales rate event specific distress                       |          |        | X      |



# CAB questions:

- *Next steps*

1. Overall study plan – questions

2. Focus group development:

- Participant selection
- Guide/survey edits

3. Next meeting



# mAGIC

MOBILE APPLICATION FOR GENETIC INFORMATION ON CANCER



## Thank you!



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MOBILE APPLICATION FOR GENETIC INFORMATION ON CANCER



Melissa Geller, MD, Co-PI

Hee Yun Lee, PhD, Co-PI

Team: Kristin Baker Niendorf, Rachel Isaksson Vogel, Sue Petzel, Matt Gerber, Heewon Lee



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# CAB Meeting

- *Introductions*
- *Study Goal*
  - Develop a mobile application to educate women with ovarian cancer about the recommendation for genetic counseling and promote update of genetic counseling services.
- *Progress since last meeting*
  - Human subjects approval from the Cancer Center, IRB, and the DOD for phase I (focus groups)
  - Conducted 4 focus groups, analysis underway
  - In process of securing local technology partner
  - Initial stages of content development for the application



# CAB Meeting

- *Goals for today*
  - Discuss preliminary results from focus groups
  - Discuss experience with the mMammogram intervention
  - Get your thoughts regarding timing and length of the intervention



# Summary of Focus Groups

- *Note: These results are preliminary.*
- *4 Groups (up from original 3 planned):*
  - Those who saw genetic counselor
  - Those who were not referred for genetic counseling
  - Those who were referred but didn't see genetic counselor
    - Didn't really know they were referred/what genetic counseling is or if it was relevant for them
    - Actively declined
- *Most women had smart phones*
- *Each slide please consider if anything is missing or how we might prioritize comments*





# Summary of Focus Groups

- *Barriers*

- Knowledge

- Most seem to understand that cancer can be hereditary, but quite a few didn't realize links between ovarian cancer and other cancers
    - Purpose of genetic counseling
    - Distinction between genetic counseling and genetic testing

- Relevance

- No children
    - Not much family history of cancer or didn't know family history

- Cost/Insurance/Insurance Discrimination

- Scared of information / having to act on information





# Summary of Focus Groups

- *Facilitators*

- Information about guidelines, purpose of genetic counseling and relevance for patient and their family
- Fear of another cancer
- Knowledge that ovarian cancer is so hard to detect early
- Physician referral / discussion
  - Important to note that many who said this HAD been referred but didn't seem to know it
- Knowledge that genetic testing can provide “actionable” information
- Concern for family members



# Summary of Focus Groups

- *Suggestions for mobile application*
  - All thought mobile application would be useful
  - SIMPLE to use
  - Provide training (in-person and written materials)
  - Clear language, not too medical
  - Positive messages (avoid fear-based messaging)
  - Short messages, with ability to access more in-depth information if desired
  - Connect with computer (website) and allow for access at later time points to review information
  - Videos would be helpful (provide information in multiple formats)
  - Be mindful to data requirements/load
  - Provide information at time of diagnosis but be prepared to revisit
  - Reminders/alerts to trigger use of the application





# Summary of Focus Groups

- *Topics to include in mobile application*
  - What is genetic counseling, why is it important
  - How information would be use (personally, family members)
  - What sub-populations are at higher risk
  - Links to other cancers
  - Importance of family history on both sides (mother and father)
  - Resources (where to go, who to call)
  - Pros AND cons
  - Cost and insurance information
  - How to discuss with family
  - Brief risk calculator
  - Quiz to assess knowledge (don't know what you don't know)
  - Outline of genetic counseling appointment



# mMAMMOGRAM

- 15-20 messages per day for 7 days
- Send each message every 30 seconds.
- Interactive message (e.g., question) takes 60 seconds
- Takes 15-20 minutes to complete each day's program
- Health navigator available for questions
- Emoticons to motivate involvement and raise interest



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# mMammogram app information

| Day | Theme                                    |
|-----|--|
| 1   | Introduction to breast cancer            |
| 2   | Introduction to breast screening methods |
| 3   | “Knowledge day”                          |
| 4   | “Accessibility day”                      |
| 5   | “Culture day”                            |
| 6   | “Clinic day”                             |
| 7   | “Summary day” _ Quiz                     |



## Comments?

- *Your overall experience with intervention*
- *Use of text, videos, images*
- *Include website with additional information?*
  - Not included in mMammogram, mentioned during focus groups



# Comments?

- *Timing and length of intervention*
  - mMammogram: 15-20 minutes each day for 7 days
  - Considerations
    - Number of topics to be covered
    - Request for short messages
    - Rental of smart phones for participants if needed



## CAB meeting

- *Next CAB meeting will be in February (TBD)*
  - Final summary of focus group data
  - Review initial content for intervention
  - Discuss recruitment plans
- *Payment for 2014-2015 in process*
  - \$300 for year
  - UMN employees – should be on Nov. 12 check
  - Non-employees – should receive a check in the mail by Nov. 15





# mAGIC

MOBILE APPLICATION FOR GENETIC INFORMATION ON CANCER



## Thank you!



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## Day 1

### TOPIC 1: Have you heard about genetic counseling for cancer?

YES



Great! Here's a little more information about it.

Genetic counseling is usually an office visit with a masters degree-trained genetic counselor to review your family history of cancer and to assist you with genetic testing, if appropriate.

Genetic counselors help you understand the complex science of genetics and help you make the right decision about genetic testing and medical care for you and your family members.

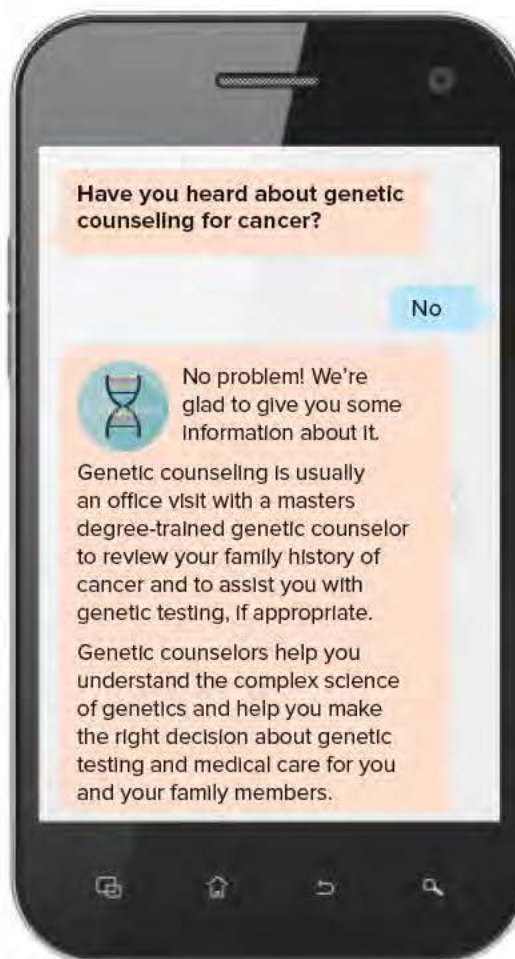
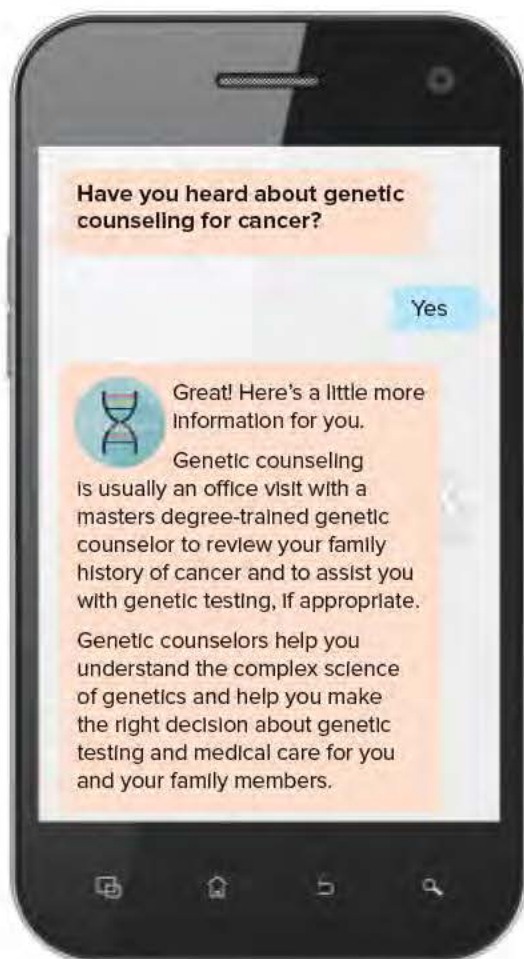
NO



No problem! We're glad to give you some information about it.

Genetic counseling is usually an office visit with a masters degree-trained genetic counselor to review your family history of cancer and to assist you with genetic testing, if appropriate.

Genetic counselors help you understand the complex science of genetics and help you make the right decision about genetic testing and medical care for you and your family members.



**TOPIC 2: Did you know that genetic counseling is recommended for all women who have or have had ovarian cancer? (This includes fallopian and primary peritoneal cancer as well.)**

YES



That's excellent! Here's a little more about some guidelines.

The Society of Gynecologic Oncology recommends that women diagnosed with epithelial ovarian, tubal, and peritoneal cancers should receive genetic counseling and be offered genetic testing, even in the absence of a family history.

The National Comprehensive Cancer Network also recommends genetic risk evaluation for ovarian cancer.

NO

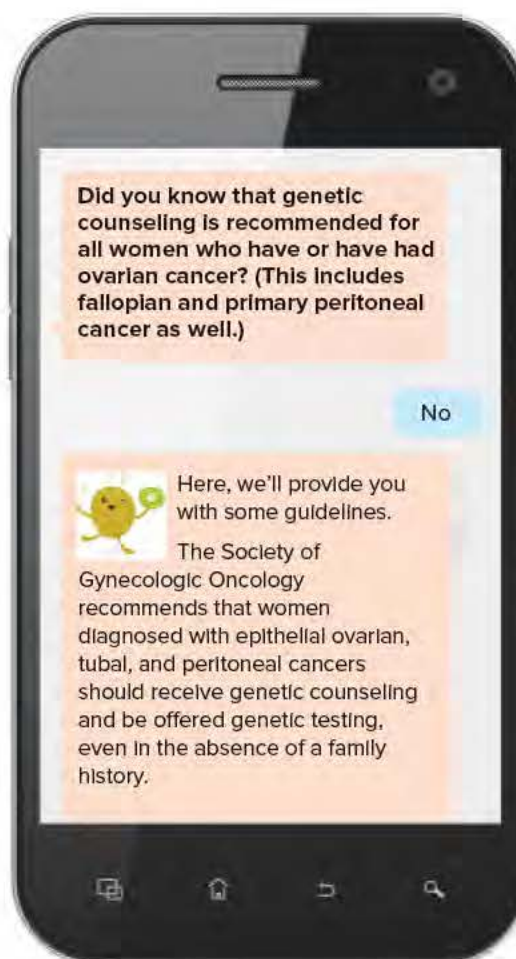
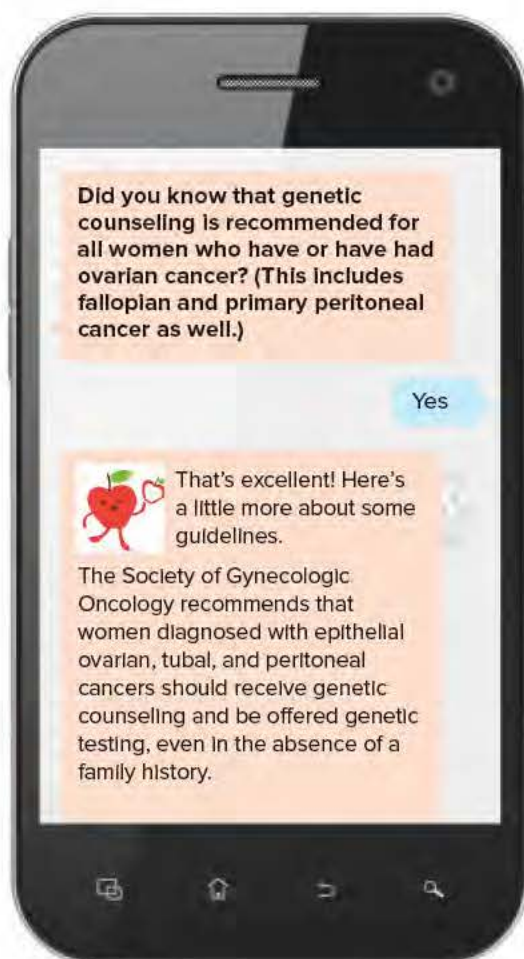


Here, we'll provide you with some guidelines.

The Society of Gynecologic Oncology recommends that women diagnosed with epithelial ovarian, tubal, and peritoneal cancers should receive genetic counseling and be offered genetic testing, even in the absence of a family history.

The National Comprehensive Cancer Network also recommends genetic risk evaluation for ovarian cancer.

**>> VIDEO OF MELISSA GELLAR DISCUSSING THE GUIDELINES**





## TOPIC 3: Do you know why genetic counseling is recommended?

YES



Superb! Here are a few key points to remember:

- 10% of ovarian cancer is hereditary
- More than one gene can cause ovarian cancer
- BRCA 1 & 2 and Lynch Syndrome often play a role in developing ovarian cancer

Here are some other clues:

- Multiple cancers in closely related family members
- More than one generation affected by cancer
- Early onset of cancer (under age XX)
- Unusual cancers
- Ashkenazi Jewish ancestry

For more information, visit the National Institutes of Health

NO



That's OK—we are here to help you learn more. Here are a few key points to remember:

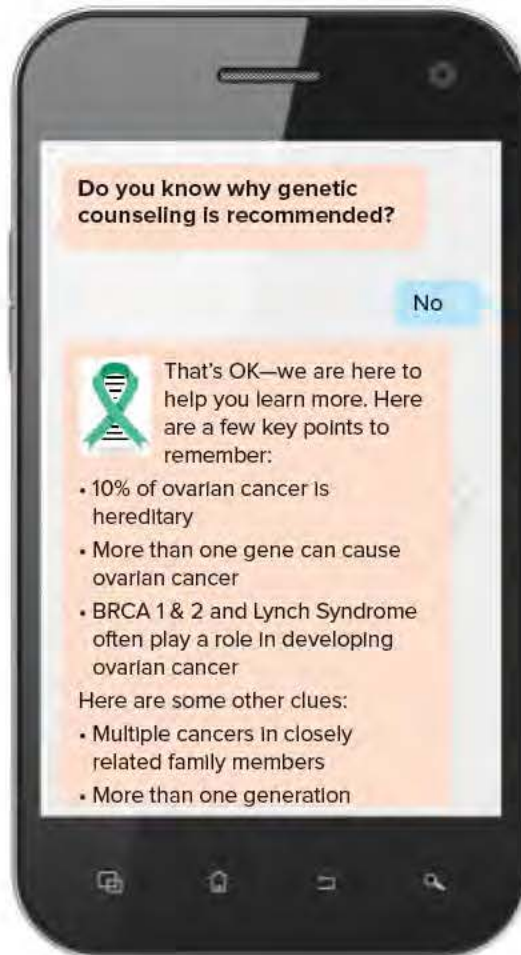
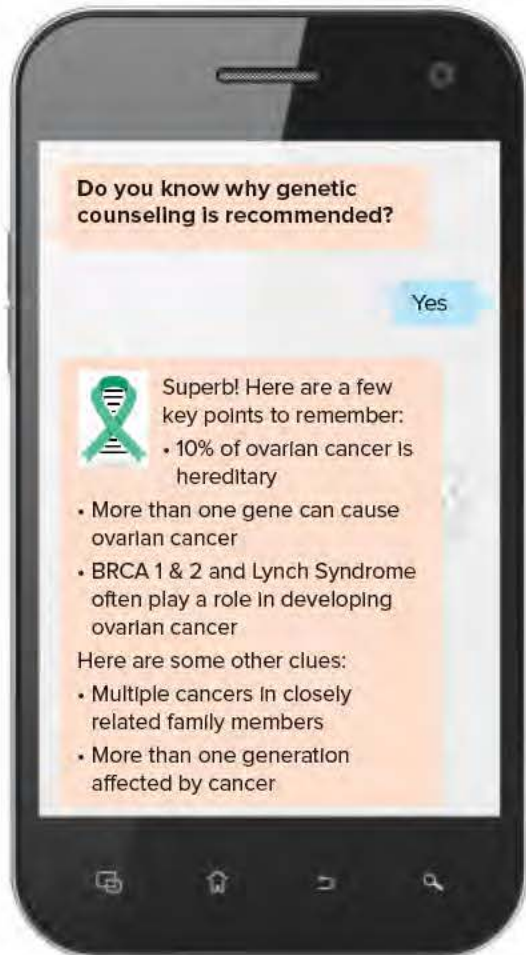
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For more information, visit the National Institutes of Health

## >> VIDEO OF KRISTIN NIENDORF FAMILY CONNECTIONS TO CANCER

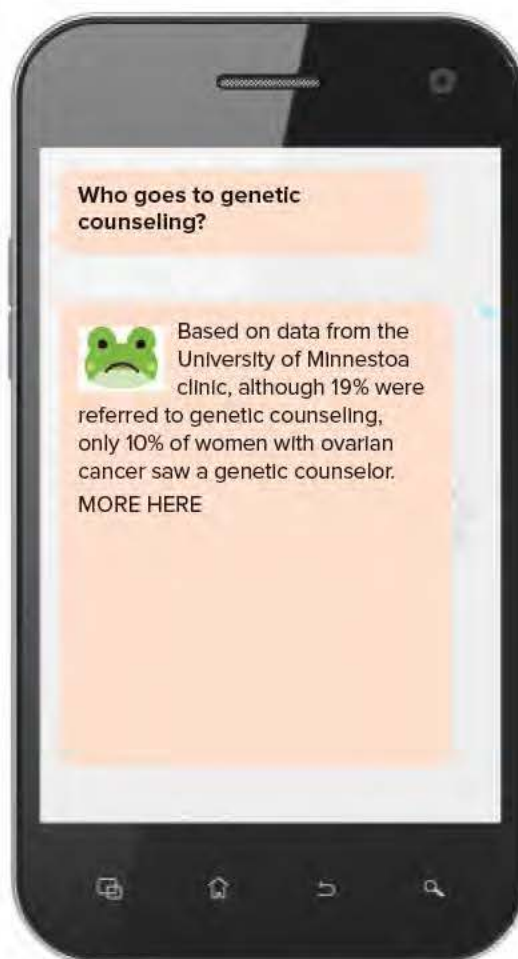




## TOPIC 4: Who goes to genetic counseling?

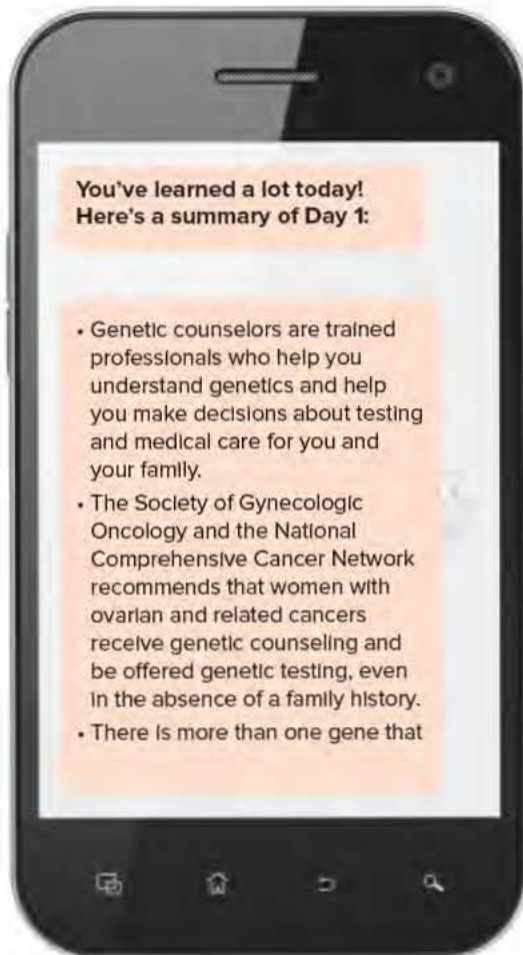
Based on data from the University of Minnesota clinic, although 19% were referred to genetic counseling, only 10% of women with ovarian cancer saw a genetic counselor.

[MORE HERE](#)



## TOPIC 5: You've learned a lot today! Here is a summary of Day 1:

- Genetic counselors are trained professionals who help you understand genetics and help you make decisions about testing and medical care for you and your family.
- The Society of Gynecologic Oncology and the National Comprehensive Cancer Network recommends that women with ovarian and related cancers receive genetic counseling and be offered genetic testing, even in the absence of a family history.
- There is more than one gene that can cause ovarian cancer and many clues from your family's health history that can help guide you in your future decisions about genetic counseling and genetic testing.
- Although there are referrals to see genetic counselors, many women with ovarian cancer do not go.  
XXXXX XXXXX XXX XXXXXXXXXXXXXXX

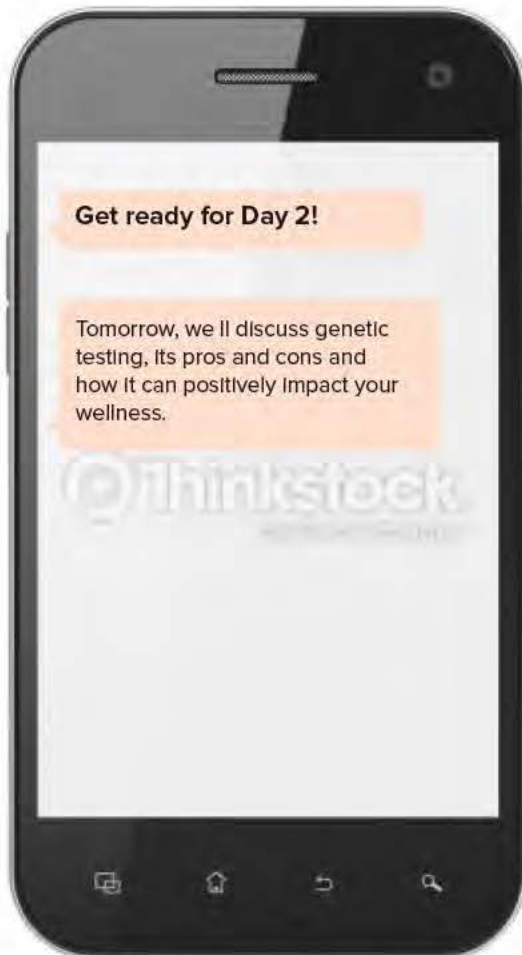




MOBILE APPLICATION FOR GENETIC INFORMATION ON CANCER

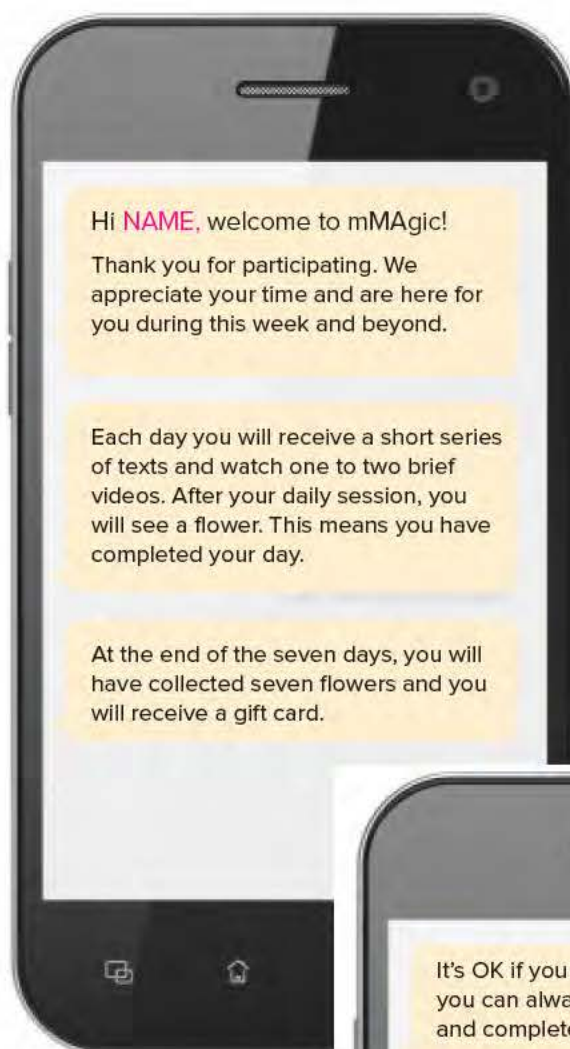
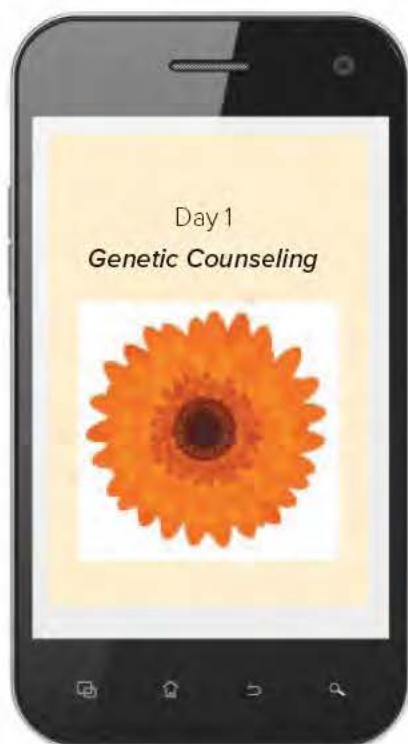
### **LAST TEXT: Get ready for Day 2!**

Tomorrow, we'll discuss genetic testing, its pros and cons and how it can positively impact your wellness.





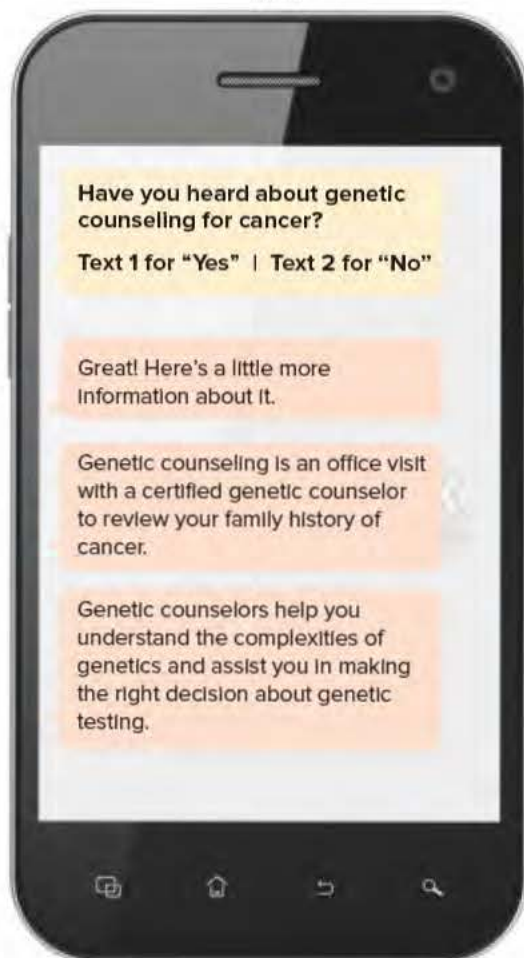
MOBILE APPLICATION FOR GENETIC INFORMATION ON CANCER



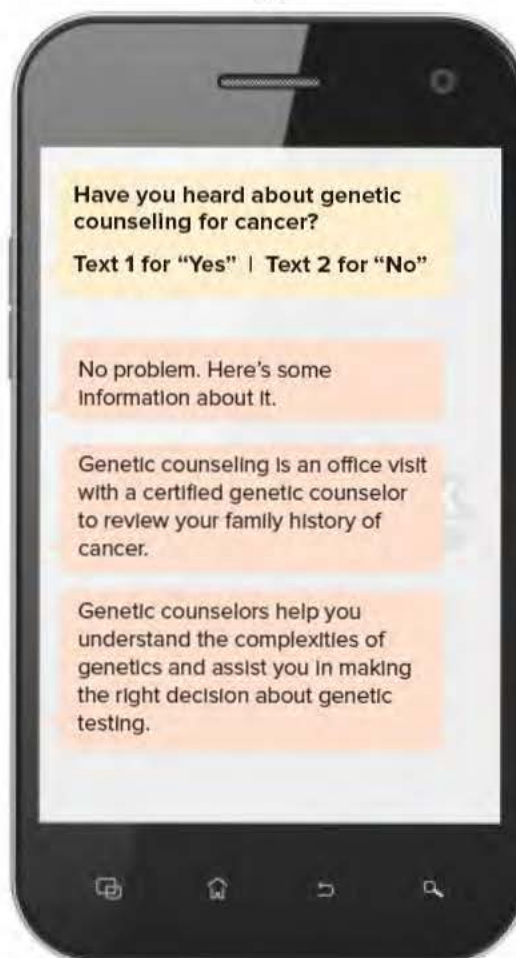


**TOPIC 1: Have you heard about genetic counseling for cancer?**

**YES**



**NO**

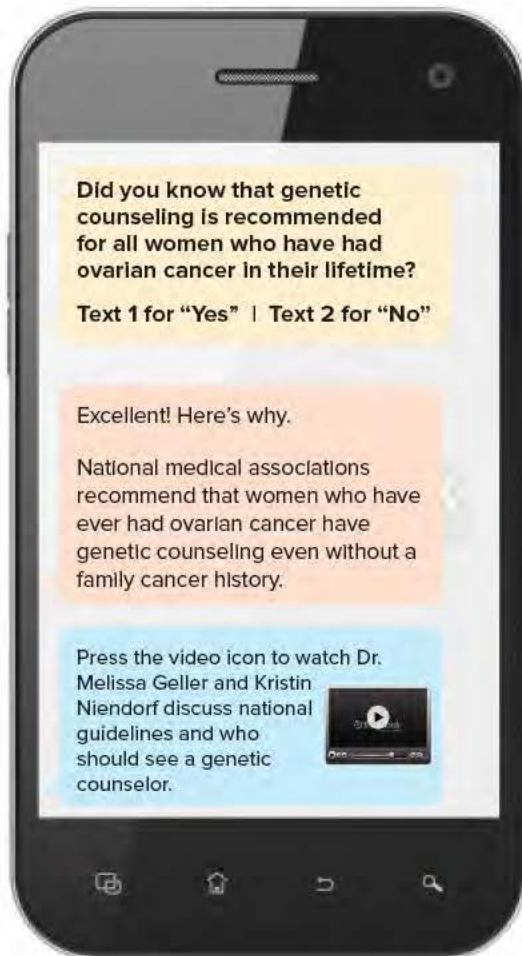


**NO ANSWER**

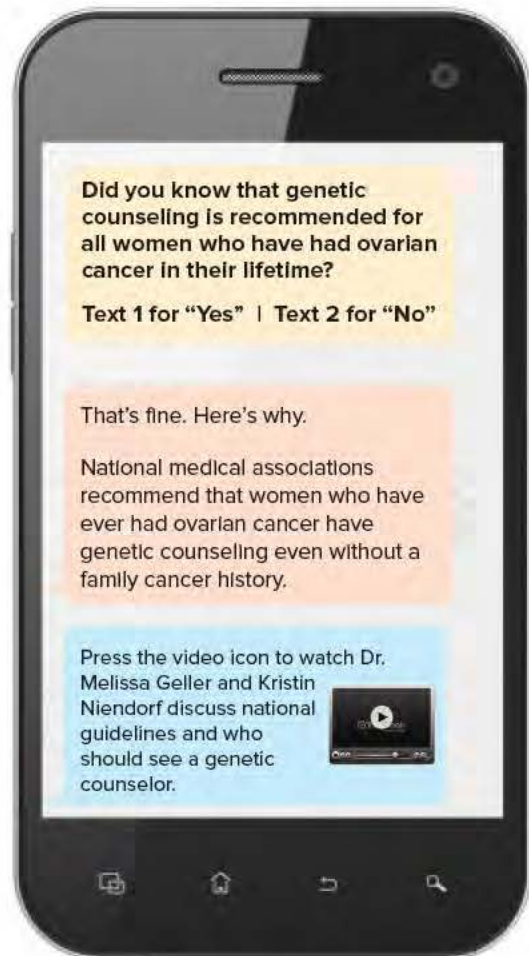


**TOPIC 2: Did you know that genetic counseling is recommended for all women who have had ovarian cancer in their lifetime?**

**YES**



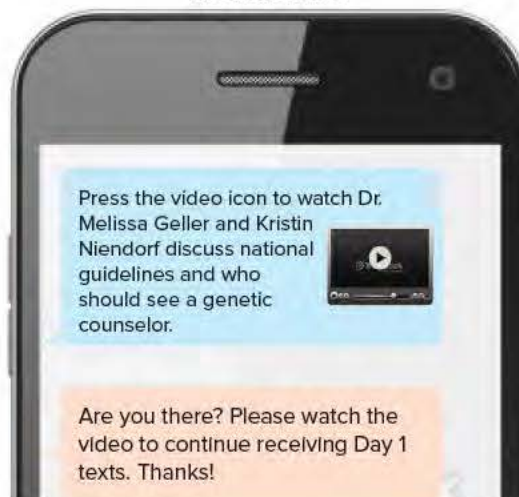
**NO**



**NO ANSWER**



**NO ANSWER**



## TOPIC 2 VIDEO

Dr. Geller, Gynecologic oncologist TOPICS

- Discuss national guidelines (QUIZ ITEM)
- Discuss who goes: anyone with ovarian cancer. (QUIZ ITEM)
- Your medical provider may have recommended that you go. Maybe not. The important thing to remember is to call.
- You don't need a referral to make an appointment.

Kristin Niendorf, Genetic counselor TOPICS

- More than one gene can cause ovarian cancer (QUIZ ITEM DAY 2)
- BRCA 1 & 2 often play a role in developing ovarian cancer (QUIZ ITEM DAY 2)
- About 15%-25% of ovarian cancer can be inherited (QUIZ ITEM)

Clues:

- Multiple cancers in closely related family members
- More than one generation affected by cancer
- Early onset of cancer (breast cancer at or below age 50)
- Unusual cancers (such as male breast cancer)
- Ashkenazi Jewish ancestry

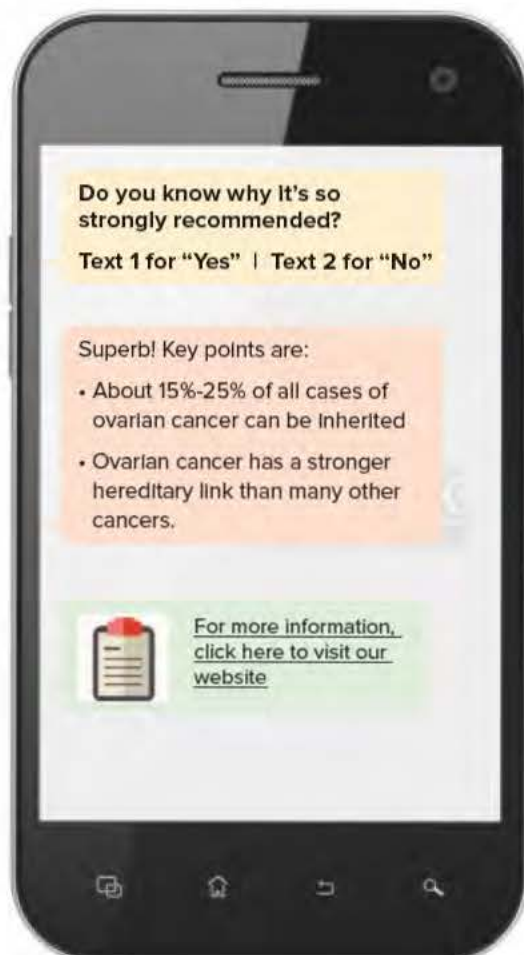
Insurance

- Some women worry, "Will my insurance pay for counseling?" Your genetic counselor can help you figure this out.

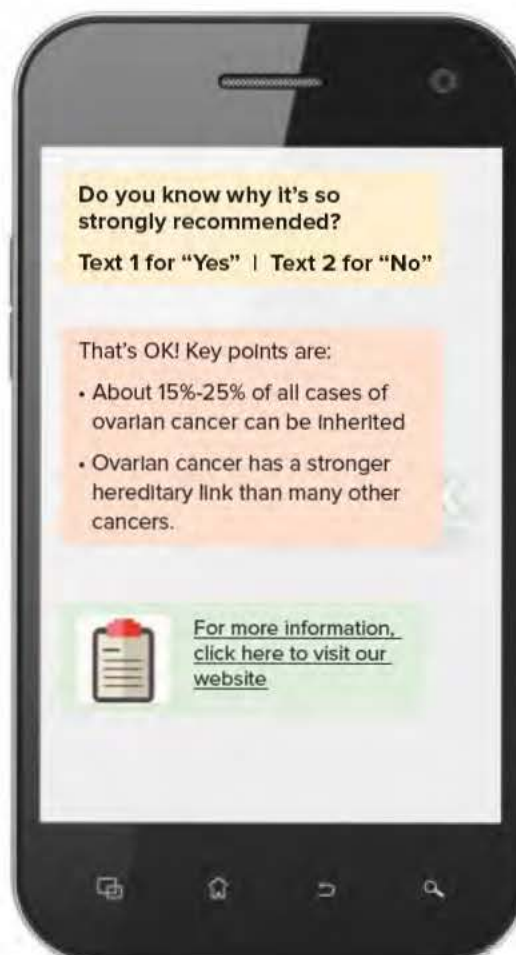
A genetic counselor is a resource to help you care for yourself.

## TOPIC 3: Do you know why it's so strongly recommended?

YES



NO



NO ANSWER





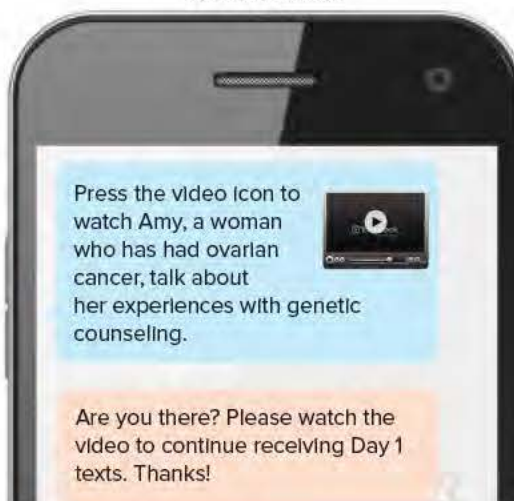
## TOPIC 3 VIDEO



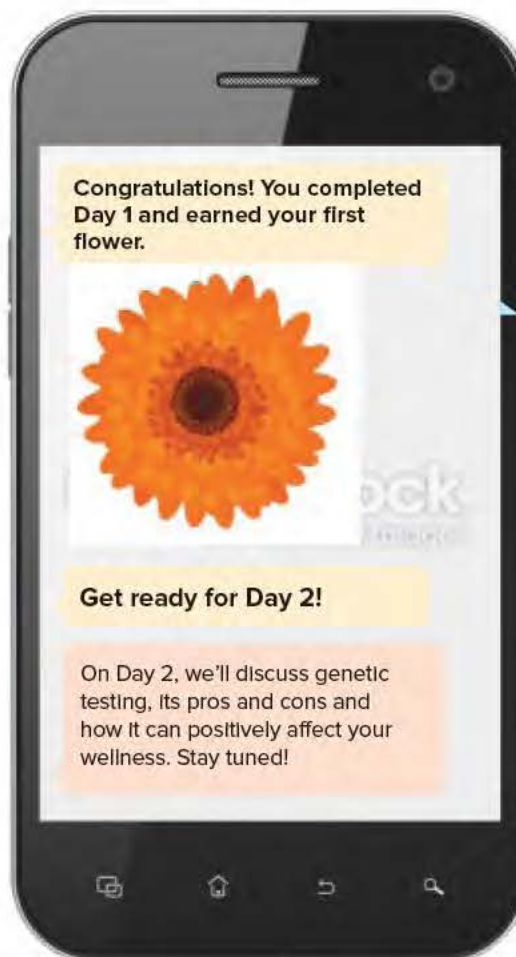
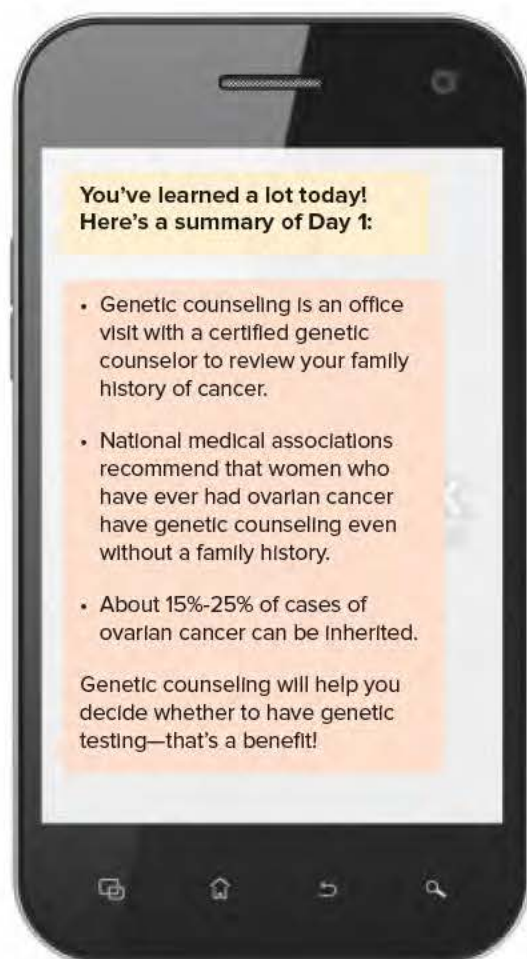
Press the video icon to watch Amy, a woman who has had ovarian cancer, talk about her experiences with genetic counseling.

- Identify hesitancy/fears
- Describe how she did to cope with action steps
- Share positive experiences
- Proactive for their health and family
- Support and promote using the mobile app/phone

## NO ANSWER



## Summary



## **Appendix E. Focus Group Moderator Guides**

### **Mobile Phone Technology to Increase Genetic Counseling for Women with Ovarian Cancer and Their Families**

#### **Moderator's Guide**

#### **Group 1 – Women with Ovarian Cancer Referred for Cancer Genetic Counseling but not seen by Genetic Counselor**

##### Overview: Conducting of the Focus Group

Focus groups with ~8 participants will be held in a small, comfortable conference room and led by a trained moderator. An assistant to the moderator will operate the recording equipment and take field notes, will check people in, distribute forms such as name tags, parking vouchers and props (described below), and handle other logistics (cookies and beverages, compensation).

The moderator will give a friendly, standard welcome, introduce participants and researchers, give a short general overview of the topic, describe the ground rules (one person speaks at a time, this will last 1-1.5 hours with a break in the middle) and pose questions. With each question, the moderator will pause for discussion, probe (“Would you explain further? Can you give an example?”), and balance participation, using subtle tactics to control dominant talkers, encourage shy participants and limit rambles.

At the end of the focus group, the moderator will give a brief (3 min.) oral summary and solicit assent/confirmation, ask if anything is missing, and thank participants. Afterwards, the moderator will be asked to read reports and comment on the researchers’ analysis.

##### Reference:

Krueger, Richard A. Focus Group Kit, Vol. 3 Developing Questions for Focus Groups Sage Publications, 1998

## ***Introduction***

Good morning and welcome to our discussion. Thank you for joining us today to discuss cancer genetic counseling. My name is Kristin and assisting me today is Rachel. We are both researchers at the University of Minnesota. We have a grant from the Department of Defense's Ovarian Cancer Research Program to develop an intervention to increase uptake of cancer genetic counseling among women with ovarian cancer.

We are interested in understanding women's perception of cancer genetic counseling and being referred for genetic counseling. We're going to talk today about your experience.

We will be audio recording and taking notes during this session. The information you provide us is important and these tools will help us remember key points. We will be on a first name basis and we will not use any names or other identifying information in our reports.

This is meant to be an informal discussion. There are no right or wrong answers. We want to hear your personal experience. Please share as much as you are comfortable. We would like to hear from everyone. You do not need to raise your hand; feel free to speak up at any time. We will take one official break, however, please feel free to get up at any time. To keep our discussion moving, we ask that you turn your cell phones on silent or vibrate and go into the hallway if you need to take a call.

### **Questions:**

1. Tell us your name and where you live (Round Robin question)
2. What is your understanding of genetic counseling for hereditary cancer?
3. Think back to when you first thought about genetic counseling:
  - a. How did you get the information about genetic counseling?
  - b. Do you perceive a benefit from obtaining cancer genetic counseling?
  - c. Do you have any concerns about seeing a genetic counselor?
4. Have you discussed genetic counseling with your family and/or friends?
5. What information about cancer genetic counseling would be helpful for women with ovarian cancer?
6. We understand being newly diagnosed can be overwhelming. Taking this into consideration, when would you like to receive this information?

**BREAK**



We are interested in women having optimal cancer care. Therefore we are interested in understanding ways to increase the use of genetic counseling among all women with ovarian cancer. We are going to use a Mobile Phone-based Application (e.g., App) to deliver educational messages via texts, pictures, and video clips.

\*\*If proportion of women with smart phones is high, ask about their favorite apps.

7. Would you find this method helpful?
8. In what ways do you see a mobile phone as a potential tool to take the best care of your health? Have you ever used a mobile application for health?
9. What would make it easy to use?
10. What might interfere with your using such a method?
11. What information would you like to receive by mobile phone?
  - a. Prompt if needed: What types of texts/pictures/video clips might help you to decide to meet with a genetic counselor?
12. What suggestions do you have for increasing genetic counseling use among women with ovarian cancer?
13. Considering everything we have discussed, did we miss anything?

## Focus Group Survey

**Directions:** No identifying information is being collected

**1. Age (years):** \_\_\_\_\_

**2. What is your race?**

- ☐ White
- ☐ Black or African American
- ☐ Other: \_\_\_\_\_

**3. Are you of Hispanic, Latino/a, or of Spanish origin?**

- ☐ No
- ☐ Yes

**4. What is the highest education level you have achieved?**

- ☐ Did not graduate high school
- ☐ High school graduate
- ☐ Some college/technical school
- ☐ College graduate
- ☐ Professional school

**5. Are you currently employed?**

- ☐ Yes – Full Time
- ☐ Yes – Part Time
- ☐ No
- ☐ Retired

**6. What is your yearly household income?**

- ☐ <\$20,000
- ☐ \$20,000-\$39,999
- ☐ \$40,000-\$79,999
- ☐ \$80,000-\$119,999
- ☐ >\$120,000

**7. Marital Status:**

- ☐ Single
- ☐ Married/Partnered
- ☐ Divorced
- ☐ Widowed

**8. Do you have biological children?**

- ☐ No
- ☐ Yes → **Number of Daughters:** \_\_\_\_\_ **Number of Sons:** \_\_\_\_\_

**9. Do you live within 30 miles of the University of Minnesota clinic?**

- ☐ Yes
- ☐ No

**10. Year of first Ovarian Cancer Diagnosis:** \_\_\_\_\_

**11. Age at first Ovarian Cancer Diagnosis:** \_\_\_\_\_

**12. Stage of Ovarian Cancer at Diagnosis:**

- ☐ I
- ☐ II
- ☐ III
- ☐ IV
- ☐ Don't Know

**13. Current Treatment Status:**

- ☐ Currently receiving treatment for first ovarian cancer diagnosis
- ☐ In surveillance, not currently receiving treatment
- ☐ Currently receiving therapy for recurrent disease
- ☐ Other \_\_\_\_\_

**14. Have you ever had another cancer?**

- ☐ No
- ☐ Yes → **What type?** \_\_\_\_\_

**15. Has anyone else in your family had cancer?**

- ☐ No

| <input type="checkbox"/> Yes → | Relation | Age at Diagnosis | Cancer Type |
|--------------------------------|----------|------------------|-------------|
|                                | _____    | _____            | _____       |
|                                | _____    | _____            | _____       |
|                                | _____    | _____            | _____       |
|                                | _____    | _____            | _____       |
|                                | _____    | _____            | _____       |

**16. Do you own a mobile phone?**

- ☐ No → Go to 16a.

**16a. If you were provided a phone for research purposes, would you participate?**

- ☐ Yes  
☐ No

- ☐ Yes → Go to 16b.

**16b. Is your phone a smart phone (in other words, can you access the internet or use applications)?**

- ☐ Yes  
☐ No

**16c. How often do you use your mobile phone?**

- ☐ Less than once per day  
☐ Approximately one time per day  
☐ Several times per day

**16d. Which of the following ways do you use your mobile phone? CHECK ALL THAT APPLY.**

- ☐ Telephone/ verbal communication  
☐ Texting (If yes, how many times do you text per day: \_\_\_\_Times)  
☐ Download and use mobile applications/games  
☐ Search the Web  
☐ Others (Specify:\_\_\_\_\_)



**Which option below reflects where you are in the decision-making process regarding cancer genetic counseling?**

- ☐ I have never thought about genetic counseling
- ☐ I am undecided about genetic counseling
- ☐ I have decided I don't want to have genetic counseling
- ☐ I have decided I do want to have genetic counseling

**Women view genetic counseling in many different ways. As you thought/think about having genetic counseling, answer whether you agree or disagree with the following statements. There are no right or wrong answers**

|   | Agree | Disagree |
|---|-------|----------|
| I see no benefit from cancer genetic counseling                                   |       |          |
| I do not know the purpose of cancer genetic counseling                            |       |          |
| I think I will be required to have genetic testing if I go                        |       |          |
| I feel/may feel overwhelmed by the information I will receive                     |       |          |
| I am concerned my medical information will not be                                 |       |          |
| I think it will be difficult to make an appointment                               |       |          |
| I am worried I or my relatives will be discriminated against by employer(s)       |       |          |
| My family is discouraging me from having genetic counseling                       |       |          |
| I think I will have difficulty finding a genetic counselor close to my home       |       |          |
| I am worried I or my relatives will face insurance discrimination                 |       |          |
| I am not sure I will not be able to get my family history information             |       |          |
| My other life events take priority to determining my cancer risk                  |       |          |
| I am concerned about paying for the genetic counseling session                    |       |          |
| I am concerned about how I will be seen if I am found to have a genetic condition |       |          |
| I have no time to seek genetic counseling now                                     |       |          |

**Other thoughts on genetic counseling:**

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Mobile Phone Technology to Increase Genetic Counseling for  
Women with Ovarian Cancer and Their Families

Moderator's Guide

**Group 2 – Women with Ovarian Cancer Not Referred to a Genetic Counselor**

Overview: Conducting of the Focus Group

Focus groups with ~8 participants will be held in a small, comfortable conference room and led by a trained moderator. An assistant to the moderator will operate the recording equipment and take field notes, will check people in, distribute forms such as name tags, parking vouchers and props (described below), and handle other logistics (cookies and beverages, compensation).

The moderator will give a friendly, standard welcome, introduce participants and researchers, give a short general overview of the topic, describe the ground rules (one person speaks at a time, this will last 1-1.5 hours with a break in the middle) and pose questions. With each question, the moderator will pause for discussion, probe (“Would you explain further? Can you give an example?”), and balance participation, using subtle tactics to control dominant talkers, encourage shy participants and limit ramblers.

At the end of the focus group, the moderator will give a brief (3 min.) oral summary and solicit assent/confirmation, ask if anything is missing, and thank participants. Afterwards, the moderator will be asked to read reports and comment on the researchers’ analysis.

Reference:

Krueger, Richard A. Focus Group Kit, Vol. 3 Developing Questions for Focus Groups Sage Publications, 1998

## ***Introduction***

Good morning and welcome to our discussion. Thank you for joining us today to discuss cancer genetic counseling. My name is Kristin and assisting me today is Rachel. We are both researchers at the University of Minnesota. We have a grant from the Department of Defense's Ovarian Cancer Research Program to develop an intervention to increase uptake of cancer genetic counseling among women with ovarian cancer.

We are interested in understanding women's perception of cancer genetic counseling. We're going to talk today about your experience.

We will be audio recording and taking notes during this session. The information you provide us is important and these tools will help us remember key points. We will be on a first name basis and we will not use any names or other identifying information in our reports.

This is meant to be an informal discussion. There are no right or wrong answers. We want to hear your personal experience. Please share as much as you are comfortable. We would like to hear from everyone. You do not need to raise your hand; feel free to speak up at any time. We will take one official break, however, please feel free to get up at any time. To keep our discussion moving, we ask that you turn your cell phones on silent or vibrate and go into the hallway if you need to take a call.

### **Questions:**

1. Tell us your name and where you live (Round Robin question)
2. What is your understanding of genetic counseling for hereditary cancer?
3. Think back to when you first thought about genetic counseling:
  - a. How and when did you get the information about genetic counseling?
  - b. Do you perceive a benefit from obtaining cancer genetic counseling?
  - c. Do you have any concerns about seeing a genetic counselor?
  - d. *If never thought about it, would you like more information genetic counseling?*
4. What factors would you take into account when making a decision about receiving genetic counseling for cancer?
5. What information about cancer genetic counseling would be helpful for women with ovarian cancer?
6. When would you like to receive this information? [prompt time of diagnosis if needed]

### **BREAK**

We are interested in women having optimal cancer care. Therefore we are interested in understanding ways to increase the use of genetic counseling among all women with ovarian cancer. We are going to use a Mobile Phone-based Application (e.g., App) to deliver educational messages via texts, pictures, and video clips.

**\*\*If proportion of women with smart phones is high, ask about their favorite apps.**

7. Would you find this method helpful and why/why not?
8. In what ways do you see a mobile phone as a potential tool to take the best care of your health?
9. What would make it easy to use?
10. What might interfere with your using such a method?
11. What information would you like to receive by mobile phone?
12. What types of texts/pictures/video clips might help you to decide to meet with a genetic counselor?  
[prompt other patients, physicians, family member videos/messages if needed]

13. What suggestions do you have for increasing genetic counseling use among women with ovarian cancer?
14. Considering everything we have discussed, did we miss anything?



## Focus Group Survey

**Directions:** No identifying information is being collected and your survey

**1. Age (years):** \_\_\_\_\_

**2. What is your race?**

- ☐ White
- ☐ Black or African American
- ☐ Other: \_\_\_\_\_

**3. Are you of Hispanic, Latino/a, or of Spanish origin?**

- ☐ No
- ☐ Yes

**4. What is the highest education level you have achieved?**

- ☐ Did not graduate high school
- ☐ High school graduate
- ☐ Some college/technical school
- ☐ College graduate
- ☐ Professional school

**5. Are you currently employed?**

- ☐ Yes – Full Time
- ☐ Yes – Part Time
- ☐ No
- ☐ Retired

**6. What is your yearly household income?**

- ☐ <\$20,000
- ☐ \$20,000-\$39,999
- ☐ \$40,000-\$79,999
- ☐ \$80,000-\$119,999
- ☐ >\$120,000

**7. Marital Status:**

- ☐ Single
- ☐ Married/Partnered
- ☐ Divorced
- ☐ Widowed

**8. Do you have biological children?**

☐ No

☐ Yes → **Number of Daughters:** \_\_\_\_\_ **Number of Sons:** \_\_\_\_\_

**9. Do you live within 30 miles of the University of Minnesota clinic?**

☐ Yes

☐ No

**10. Year of first Ovarian Cancer Diagnosis:** \_\_\_\_\_

**11. Age at first Ovarian Cancer Diagnosis:** \_\_\_\_\_

**12. Stage of Ovarian Cancer at Diagnosis:**

☐ I

☐ II

☐ III

☐ IV

☐ Don't Know

**13. Current Treatment Status:**

☐ Currently receiving treatment for first ovarian cancer diagnosis

☐ In surveillance, not currently receiving treatment

☐ Currently receiving therapy for recurrent disease

☐ Other \_\_\_\_\_

**14. Have you ever had another cancer?**

☐ No

☐ Yes → **What type?** \_\_\_\_\_

**15. Has anyone else in your family had cancer?**

☐ No

| <input type="checkbox"/> Yes → | Relation | Age at Diagnosis | Cancer Type |
|--------------------------------|----------|------------------|-------------|
|                                | _____    | _____            | _____       |
|                                | _____    | _____            | _____       |
|                                | _____    | _____            | _____       |
|                                | _____    | _____            | _____       |
|                                | _____    | _____            | _____       |

**16. Do you own a mobile phone?**

☐ No → Go to 16a.

**16a. If you were provided a phone for research purposes, would you participate?**

☐ Yes

☐ No

☐ Yes → Go to 16b.

**16b. Is your phone a smart phone (in other words, can you access the internet or use applications)?**

☐ Yes

☐ No

**16c. How often do you use your mobile phone?**

☐ Less than once per day

☐ Approximately one time per day

☐ Several times per day

**16d. Which of the following ways do you use your mobile phone? CHECK ALL THAT APPLY.**

☐ Telephone/ verbal communication

☐ Texting (If yes, how many times do you text per day: \_\_\_\_Times)

☐ Download and use mobile applications/games

☐ Search the Web

☐ Others (Specify:\_\_\_\_\_)

**Which option below reflects where you are in the decision-making process regarding cancer genetic counseling?**

- ☐ I have never thought about genetic counseling
- ☐ I am undecided about genetic counseling
- ☐ I have decided I don't want to have genetic counseling
- ☐ I have decided I do want to have genetic counseling

**Women view genetic counseling in many different ways. As you thought/think about having genetic counseling, answer whether you agree or disagree with the following statements. There are no right or wrong answers**

|   | Agree | Disagree |
|---|-------|----------|
| I see no benefit from cancer genetic counseling                                   |       |          |
| I do not know the purpose of cancer genetic counseling                            |       |          |
| I think I will be required to have genetic testing if I go                        |       |          |
| I feel/may feel overwhelmed by the information I will receive                     |       |          |
| I am concerned my medical information will not be                                 |       |          |
| I think it will be difficult to make an appointment                               |       |          |
| I am worried I or my relatives will be discriminated against by employer(s)       |       |          |
| My family is discouraging me from having genetic counseling                       |       |          |
| I think I will have difficulty finding a genetic counselor close to my home       |       |          |
| I am worried I or my relatives will face insurance discrimination                 |       |          |
| I am not sure I will not be able to get my family history information             |       |          |
| My other life events take priority to determining my cancer risk                  |       |          |
| I am concerned about paying for the genetic counseling session                    |       |          |
| I am concerned about how I will be seen if I am found to have a genetic condition |       |          |
| I have no time to seek genetic counseling now                                     |       |          |

**Other thoughts on genetic counseling:**

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Mobile Phone Technology to Increase Genetic Counseling for  
Women with Ovarian Cancer and Their Families

Moderator's Guide

**Group 3: Women with Ovarian Cancer Seen by Genetic Counselor**

Overview: Conducting of the Focus Group

Focus groups with ~8 participants will be held in a small, comfortable conference room and led by a trained moderator. An assistant to the moderator will operate the recording equipment and take field notes, will check people in, distribute forms such as name tags, parking vouchers and props (described below), and handle other logistics (cookies and beverages, compensation).

The moderator will give a friendly, standard welcome, introduce participants and researchers, give a short general overview of the topic, describe the ground rules (one person speaks at a time, this will last 1-1.5 hours with a break in the middle) and pose questions. With each question, the moderator will pause for discussion, probe (“Would you explain further? Can you give an example?”), and balance participation, using subtle tactics to control dominant talkers, encourage shy participants and limit rambles.

At the end of the focus group, the moderator will give a brief (3 min.) oral summary and solicit assent/confirmation, ask if anything is missing, and thank participants. Afterwards, the moderator will be asked to read reports and comment on the researchers’ analysis.

Reference:

Krueger, Richard A. Focus Group Kit, Vol. 3 Developing Questions for Focus Groups Sage Publications, 1998

## ***Introduction***

Good morning and welcome to our discussion. Thank you for joining us today to discuss cancer genetic counseling. My name is Kristin and assisting me today is Rachel. We are both researchers at the University of Minnesota. We have a grant from the Department of Defense's Ovarian Cancer Research Program to develop an intervention to increase uptake of cancer genetic counseling among women with ovarian cancer.

We are interested in women's experience with cancer genetic counseling.

We will be audio recording and taking notes during this session. The information you provide us is important and these tools will help us remember key points. We will be on a first name basis and we will not use any names or other identifying information in our reports.

This is meant to be an informal discussion. There are no right or wrong answers. We want to hear your personal experience. Please share as much as you are comfortable. We would like to hear from everyone. You do not need to raise your hand; feel free to speak up at any time. We will take one official break, however, please feel free to get up at any time. To keep our discussion moving, we ask that you turn your cell phones on silent or vibrate and go into the hallway if you need to take a call.

### **Questions:**

1. Tell us your name and where you live (Round Robin question)
2. What is your understanding of genetic counseling for hereditary cancer?
3. Think back to when you first thought about genetic counseling:
  - a. How did you get the information about genetic counseling?
  - b. What were your concerns about seeing a genetic counselor?
  - c. Did you ever consider not seeing a genetic counselor? If so why? What convinced you to go to the genetic counselor?
4. What factors would you take into account when making a decision about receiving genetic counseling for cancer?
5. What information about cancer genetic counseling would be helpful for women with ovarian cancer? What would you tell a woman who is considering going to a genetic counselor but has not made the decision to do so?
6. Do you regret seeing a genetic counselor for any reason?
7. Did you tell your family that you saw a genetic counselor? If you were tested for a gene mutation did you pass the results of the testing on to your family members? How did you tell them? Would you have liked to tell them in another way?

**BREAK**

We are interested in women having optimal cancer care. Therefore we are interested in understanding ways to increase the use of genetic counseling among all women with ovarian cancer. We are going to use a Mobile Phone-based Application (e.g., App) to deliver educational messages via texts, pictures, and video clips.

\*\*If proportion of women with smart phones is high, ask about their favorite apps.

8. Would you find this method helpful?
9. In what ways do you see a mobile phone as a potential tool to take the best care of your health?
10. What would make it easy to use?
11. What might interfere with your using such a method?
12. What information would you like to receive by mobile phone?
13. What types of texts/pictures/video clips might help you to decide to meet with a genetic counselor?  
[prompt other patients, physicians, family member videos/messages if needed]
14. What suggestions do you have for increasing genetic counseling use among women with ovarian cancer?
15. Considering everything we have discussed, did we miss anything?

## Focus Group Survey

**Directions:** No identifying information is being collected and your survey will be

**1. Age (years):** \_\_\_\_\_

**2. What is your race?**

- ☐ White
- ☐ Black or African American
- ☐ Other: \_\_\_\_\_

**3. Are you of Hispanic, Latino/a, or of Spanish origin?**

- ☐ No
- ☐ Yes

**4. What is the highest education level you have achieved?**

- ☐ Did not graduate high school
- ☐ High school graduate
- ☐ Some college/technical school
- ☐ College graduate
- ☐ Professional school

**5. Are you currently employed?**

- ☐ Yes – Full Time
- ☐ Yes – Part Time
- ☐ No
- ☐ Retired

**6. What is your yearly household income?**

- ☐ <\$20,000
- ☐ \$20,000-\$39,999
- ☐ \$40,000-\$79,999
- ☐ \$80,000-\$119,999
- ☐ >\$120,000

**7. Marital Status:**

- ☐ Single
- ☐ Married/Partnered
- ☐ Divorced
- ☐ Widowed



**8. Do you have biological children?**

- ☐ No
- ☐ Yes → **Number of Daughters:** \_\_\_\_\_ **Number of Sons:** \_\_\_\_\_

**9. Do you live within 30 miles of the University of Minnesota clinic?**

- ☐ Yes
- ☐ No

**10. Year of first Ovarian Cancer Diagnosis:** \_\_\_\_\_

**11. Age at first Ovarian Cancer Diagnosis:** \_\_\_\_\_

**12. Stage of Ovarian Cancer at Diagnosis:**

- ☐ I
- ☐ II
- ☐ III
- ☐ IV
- ☐ Don't Know

**13. Current Treatment Status:**

- ☐ Currently receiving treatment for first ovarian cancer diagnosis
- ☐ In surveillance, not currently receiving treatment
- ☐ Currently receiving therapy for recurrent disease
- ☐ Other \_\_\_\_\_

**14. Have you ever had another cancer?**

- ☐ No
- ☐ Yes → **What type?** \_\_\_\_\_

**15. Has anyone else in your family had cancer?**

- ☐ No

| <input type="checkbox"/> Yes → | Relation | Age at Diagnosis | Cancer Type |
|--------------------------------|----------|------------------|-------------|
|                                | _____    | _____            | _____       |
|                                | _____    | _____            | _____       |
|                                | _____    | _____            | _____       |
|                                | _____    | _____            | _____       |
|                                | _____    | _____            | _____       |

**16. Do you own a mobile phone?**

☐ No → Go to 16a.

**16a. If you were provided a phone for research purposes, would you participate?**

☐ Yes

☐ No

☐ Yes → Go to 16b.

**16b. Is your phone a smart phone (in other words, can you access the internet or use applications)?**

☐ Yes

☐ No

**16c. How often do you use your mobile phone?**

☐ Less than once per day

☐ Approximately one time per day

☐ Several times per day

**16d. Which of the following ways do you use your mobile phone? CHECK ALL THAT APPLY.**

☐ Telephone/ verbal communication

☐ Texting (If yes, how many times do you text per day: \_\_\_\_Times)

☐ Download and use mobile applications/games

☐ Search the Web

☐ Others (Specify:\_\_\_\_\_)

**We are interested in your experience with cancer genetic counseling.**

**Where/who did you first hear about genetic counseling from?**

---

**Did you receive a referral for genetic counseling?**

☐ No

☐ Yes → Who made the referral? \_\_\_\_\_

**Did you have difficulty making an appointment?**

☐ No

☐ Yes

**Did you have medical insurance at the time of your genetic counseling appointment?**

☐ No

☐ Yes → What type(s)? \_\_\_\_\_

**How much did you pay out-of-pocket for your genetic counseling appointment? \$ \_\_\_\_\_**

## Appendix F. Focus Group Moderator Summaries

### Mobile Phone Technology to Increase Genetic Counseling for Women with Ovarian Cancer and Their Families

#### ***Focus Group – Those who have already seen Genetic Counselor***

- Monday October 6, 2014
- 10am-12noon
- Moos Towers 12<sup>th</sup> floor
- Moderator: Kristin Baker Niendorf
- Co-Moderator: Rachel Isaksson Vogel

#### **N=7 (one came about 30 minutes late due to hospital procedure running late)**

*\*it was a little hard to keep them on task at times but it was clear they benefited from being in the same room as others with similar experiences and they were trading ideas and advice*

#### Demographics:

- Age range: 46-79 years old
- Most in surveillance following first diagnosis, one just finished treatment for recurrence, one about to start treatment for recurrence
- All received genetic testing, some received genetic counseling; 2-3 were positive for BRCA (one with variant)
- All own mobile phone, 6 of 7 were smart phones, 4 have used mobile apps

#### Preliminary summary:

#### **What is your understanding of genetic counseling for hereditary cancer?**

- Most discussed genetic testing, seemed to have a fairly accurate idea of what testing was
- One noted the difference between genetic counseling and testing (note: she was from MOCA, BRCA+ herself, clearly most educated on the topic)
- A few brought up the importance of family right away here

#### **Think back to when you first thought about genetic counseling (how did you get the information, what were your concerns, did you ever consider not seeing a genetic counselor)?**

- One noted a general interest in genetics and family history
- One said her doctor brought it up at the time of her first diagnosis but she was concerned about money and insurance and so waited until recurrence
- One had testing done a long time ago (~14 years) and there was no genetic counselor, just test and call about positive result; doctor never mentioned importance of father's family cancer history
- One had the doctor bring it up as she was finishing surgery; she hadn't even considered the possibility of it being genetic (she was very young at diagnosis, ~45 years old); chose to do it because of her family (she has no children but siblings)
- One noted being very nervous and anxious about it but did it for her family (no children, has siblings)
- One said she was curious

#### **Did you tell your family that you saw a genetic counselor?**

- Most said they spoke with family (some distraction here because 7<sup>th</sup> person arrived)
- One said she had a difficult conversation with her brother, he refused to be tested



- Later in the session a few noted that there is a history of families not talking about medical issues and that hopefully that will change starting with their generation
- They felt it was important for families to acknowledge that they are still here and LIVING with cancer (not dying) and that it is ok to talk about cancer

**Do you regret seeing a genetic counselor for any reason?**

- Most said no
- One noted concern about genetic testing because of “pre-existing condition” issue and insurance
- A few others brought up insurance and costs

**What information about cancer genetic counseling would be helpful for women with ovarian cancer? What would you tell a woman who is considering going to a genetic counselor but has not made the decision to do so?**

- One noted that since ovarian cancer is so hard to detect, knowing if you have the gene(s) can help catch it earlier since you know to look
- One reiterated that she was personally afraid but put her family first
- One noted the importance of laying out the pros and cons and to address possible concerns (for her, insurance and cost)
- One caught her ovarian cancer at stage 1 during prophylactic hyst after discovering BRCA positive following breast cancer, so she was thankful it was caught early
- One noted she is an information seeker and so it helped her feel more in control to have more information
- One person came back to the distinction between genetic counseling and testing and thought it was important to know that genetic counseling is NOT testing and is meant to provide information and options
- A few brought up the importance of educating physicians as not all of them received this information from their physician
- Many, in some form, articulated that genetic counseling/testing was good information for them because it was actionable (i.e. have family tested, take prophylactic measures, etc.)

-----

**Would you find (a mobile application) useful and what information would you like to receive?**

- Most said yes, especially for the “younger” women who will continue to experience this disease
- Information regarding which cancers are connected (she noted breast cancer in her family and said she was really only looking for breast cancer, didn’t realize the connection with ovarian cancer)
- Thought it was important to include the guidelines (i.e. NCCN, etc.) or connect with the American Cancer Society to help legitimize the need
- Many noted that is important not to include too much information, which can be overwhelming
- A few noted the need for it to be positive (some received information from others re: poor prognosis and found it very troubling)
- One woman said specifically: what is it (genetic counseling), why it is important, what sub-populations are at higher risk, resources, and benefits

- A few noted that it needed to use simple/clear language and not be too medically oriented (quite a few noted chemo brain, etc.)
- A few thought video clips from survivors and information on how to talk to family would be beneficial
- One noted fear of data load (i.e. would need to be careful to warn participants or ask make sure they can access internet before viewing)
- One added that she didn't know what she didn't know and thought it would be helpful to ask the participant questions through the phone to determine what information they might need or would be relevant to them (she noted that she didn't even know how to say Ashkenazi Jew whereas that was clearly important for a few women in the room with that ancestry and their risks)

**In what ways do you see a mobile phone as a potential tool to take the best care of your health?**

- Easy information, quick, always with you
- One person mentioned having all of your cancer treatment, history, etc. information at your fingertips (another person mentioned myChart and her reliance on it for appointments)
- One person thought it might be good to include a brief risk calculator
- Outline of genetic counseling session, what types of questions would be asked (to demystify the process, make it less scary) and provide link to number
- Thought it would be a good way to easily include/share information with family
- A few brought up questions regarding dissemination – concern about women knowing how to access this application and that it existed

## **Mobile Phone Technology to Increase Genetic Counseling for Women with Ovarian Cancer and Their Families**

### ***Focus Group – Those referred for GC but did not attend, unaware of purpose***

- Thursday October 9, 2014
- 3-5pm
- Moos Towers 12<sup>th</sup> floor
- Moderator: Kristin Baker Niendorf
- Co-Moderator: Rachel Isaksson Vogel

**N=2**

*\*we ended up going off the script a bit because it was hard to ask questions about genetic counseling relating to cancer as they hadn't really heard of it or told anything about its relation with ovarian cancer*

### Demographics:

- Ages: 51, 66
- One was recently diagnosed (just completed treatment), the other had germ-cell disease at age 26 (25 years ago; heard about study through MOCA)
- One owned smart phone, other did not have a cell phone

### Preliminary Summary:

#### **What is your understanding of genetic counseling for hereditary cancer?**

- Never heard about it related to ovarian cancer, don't know much about it
- Knew of general idea of genetic counseling (related to pregnancy)

#### **Have you thought about genetic counseling related to your ovarian cancer diagnosis?**

- Never really thought about it as related
- Never heard about it from doctor so hadn't considered it
- Do know that some cancers may be hereditary

#### **Would you like more information about genetic counseling and ovarian cancer?**

- One said "scientist" in me would like more information
- Concern for family members (see that as a benefit of genetic counseling)
- One was not sure if she would want to know – she was the first person in her family with cancer

#### **Kristin explained genetic counseling a little bit and that ~15% of ovarian cancer is thought to be hereditary. Given that, what information about cancer genetic counseling would be helpful for women with ovarian cancer?**

- Statistics (one stated she thought 15% was low and that was important to reiterate)
- Spread the information as some people have never heard of it
- Highlight the family risks

#### **Kristin then explained the purpose of genetic counseling (discuss personal and family risk of cancer, explain testing results if testing is pursued). Given this information, what concerns would you have about genetic counseling and testing?**

- Wouldn't want to invoke fear (needs to be information based, not fear based)

- Both noted out of pocket expense
- Insurance discrimination and expense
- One stated she would go if doctor recommended

---

**Would you find (a mobile application) useful and what information would you like to receive?**

- Both said yes
  - Woman without cell phone said that she thought it was a better avenue to reach more people than TV
  - Other woman said yes, but would be nice if information was accessible by computer as well because she prefers the computer to go on the internet

**In what ways do you see a mobile phone as a potential tool to take the best care of your health?**

- See it as useful for tracking appointments, reminders
- Finds it a little scary for tracking records – worries about security

**What would make it easy to use?**

- Offer training

**What might interfere with such a method?**

- If it isn't relevant or useful

**What information would you like to receive by mobile phone?**

- General/broad information and then provide link for more specific information
- Text or email as prompt
- Alert/trigger to look more often
- Short message to determine if relevant (short and sweet) and then link to further information/video
- Can't be too much/long if daily/frequent messages

**What suggestions do you have for increasing genetic counseling use among women with ovarian cancer?**

- Provide relevant information
- Best to get information right away (at time of diagnosis) but be prepared to revisit later at other time points in case it isn't acted upon immediately
- Provide information about where to go for genetic counseling

**Any other suggestions?**

- One mentioned she thought it was important that users retain access to the information to revisit at a later time if they want
- Use a quiz or other way to engage and determine what is known/unknown

## **Mobile Phone Technology to Increase Genetic Counseling for Women with Ovarian Cancer and Their Families**

### ***Focus Group – Those referred for GC but did not attend, unaware of purpose***

- Monday October 13, 2014
- 1-3pm
- Moos Towers 12<sup>th</sup> floor
- Moderator: Kristin Baker Niendorf
- Co-Moderator: Rachel Isaksson Vogel

**N=2**

*\*similar to group on October 9; they knew little about genetic counseling and its purpose related to cancer*

### Demographics:

- Ages: 58, 59
- Diagnosed 1-3 years ago, both in surveillance
- One owned smart phone, other had regular phone (said owned smart phone but never opened it)

### Preliminary summary:

#### **What is your understanding of genetic counseling for hereditary cancer?**

- Not really sure what it is
- Both reported getting some information from nurses recently but didn't really know exactly what it was / purpose / if it was relevant for them
- One confused it with HPV testing related to Pap smear
- One noted up front that she doesn't have children and not sure it is relevant for her
- They did understand that some medical issues can be hereditary (one noted heart disease runs in her family)

**Since neither person was familiar, Kristin explained what genetic counseling is, the rates of hereditary cancer in those with ovarian/FT/PP and the recent NCCN guidelines.**

#### **Do you feel there is a benefit of genetic counseling?**

- One said yes, but would only pursue if she got another cancer
- One said sees the value in it as she has daughters, could be important for family

#### **Would you share this information with your family? And how?**

- One said yes – she talks with her family frequently, would talk about in person
- One said she is less connected with her family (they are not aware of her cancer diagnosis) but she would tell them if she got pertinent information – mentioned sending a letter

#### **Do you have any concerns about genetic counseling and testing?**

- The information could potentially be scary
- One stated she doesn't know enough to know the cons, but doesn't see value since she doesn't have children
- One stated she doesn't know her family history well and doesn't talk with her family much so that would be difficult for her



**What information about cancer genetic counseling would be helpful for women with ovarian cancer?**

- One stated the more information the better
- Statistics
- Helpful to know how information will be used (i.e. family discussions, prophylactic options)
- Information on how to share with family
- [Rachel note: It seemed that both did not understand that there could be risk to their male family members]

**We understand being newly diagnosed can be overwhelming. Taking this into consideration, when would you like to receive this information?**

- One stated after second visit – was initially in denial about cancer diagnosis, needed to process
- Noted that a written/print form of information is important so it is accessible later to process / remember
- One said she wanted information ASAP; she noted that for her information is helpful but acknowledged it is also overwhelming

**If doctor recommended genetic counseling, would you go?**

- Both said yes

**If not prompted by doctor, what else might prompt you to go?**

- One noted there is a flyer in the clinic that prompted her to ask her provider about it, though she doesn't recall their conversation
- Information – needs to be provided regarding not only children's risk, but personal and extended family risks

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**Would you find (a mobile application) useful and what information would you like to receive?**

- Both said yes
- One noted she liked that it could give information in different formats and that it could be short

**What would make it easy to use?**

- Simple
- Having kids or family members around to help with technical questions/issues
- Training – providing both in-person and written materials for use

**What might interfere with such a method?**

- Small screen size – one person recommended it be available on both mobile and computer as she is more comfortable using the internet on her computer

**What type of information (text/pictures/video) would you like to receive by mobile phone?**

- Texts – need to be short
- Videos would be helpful – good to have multiple ways to get information across
- Careful not to scare with too much information

**What information would you like to receive about genetic counseling via mobile phone?**

- Information about cost, insurance
  - Both noted that just the name makes it sound expensive
- Keep it simple
- Don't know what don't know

**Any other suggestions?**

- Important to provide written and verbal information

## **Mobile Phone Technology to Increase Genetic Counseling for Women with Ovarian Cancer and Their Families**

### ***Focus Group – Those referred for GC but actively declined***

- Monday November 3, 2014
- 10am-12noon
- Mayo C278
- Moderator: Kristin Baker Niendorf
- Co-Moderator: Rachel Isaksson Vogel

**N=3**

#### Demographics:

- Ages: 56-67
- Diagnosed 1-3 years ago, in surveillance
- One owned smart phone, other two had regular phones

#### Preliminary summary:

#### **What is your understanding of genetic counseling for hereditary cancer?**

- One not really sure what it is, mentioned Angelina Jolie though as information source
- Other two seemed to have fairly good idea what it is, understood they had been referred and why

#### **Thoughts regarding genetic counseling for hereditary cancer**

- All seemed to think it was important information to have but at least two of the three of them found it overwhelming and associated with negative thoughts
- One said her family never really spoke about cancer and her culture taught her to be accepting of illness and death and so it hadn't really occurred to her to consider genetic counseling/testing
- At least one said she is not an information seeker and another admitted she thought knowing if she did in fact have a gene mutation it would negatively affect her QOL and she didn't want to "live life in dread" [Note: she had cancer 3-4x by this point – 2 rounds of breast cancer and then ovarian cancer, currently being evaluated for recurrence]
- Both who seemed pretty nervous about or against idea of having genetic counseling/testing had children and reported their children were nervous about it and seemed to be taking appropriate actions with their doctors even though they had not been tested. It seemed as if they didn't personally want the information but understood it might be important to their family and at least one admitted having some guilt over that.
- They all noted that they thought it would be cost-prohibitive at one time but do not believe that to be the case. There was a little concern about insurance or other discrimination pending results.

#### **We understand being newly diagnosed can be overwhelming. Taking this into consideration, when would you like to receive this information?**

- All said time of diagnosis is very overwhelming and that maybe information could be presented at that time but might not be processed
- One said for her it was brought up following completion of chemotherapy and she thought that was appropriate

- One thought it should be more common knowledge and part of routine/general care so that it would be so surprising and overwhelming to come up at time of cancer diagnosis

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**Would you find (a mobile application) useful?**

- All said yes
- Liked that it can be accessed when you want it/convenient
- Accurate information that can be shared with other people
  - A few noted that this can be really important when experience chemo brain and liked that they could easily reference something and share

**What would make it easy to use?**

- Have a FAQ section, glossary or way to look up medical terms if unfamiliar
- Possibility to email someone if you have a question and get response within 1-3 days
- Training, but more importantly written instructions with pictures/diagrams
- Ability to do as little or as much at any one time as desired

**What might interfere with your using such a method?**

- Don't know how to use mobile phone in that way
- Information too overwhelming or negative

**What type of information (text/pictures/video) would you like to receive by mobile phone?**

- Videos plus written information
- Make sure all messages and information can be kept and accessed at a later time
- Possibly have messages sent as email as well
- Daily texts or other more persuasive messaging might be more useful after the participant has enough information about genetic counseling is

**What information would you like to receive about genetic counseling via mobile phone?**

- What is it, pros and cons
- How to talk to family

**Any other suggestions?**

- Make available when the person is ready "on my time, my terms"

## **Appendix G. Focus Group Results of Thematic Analysis**

### **mAGIC Focus Group Data**

**Combined codes from each reviewer (MG, SP, HL) into proposed themes; placed in order based on number of times mentioned**

GC = genetic counseling; GT = genetic testing

#### **Themes underlying all categories:**

- Emotion (particularly fear) and negative attitudes--identified as barriers. Negative emotions might especially be addressed by using video (with patient and genetic counselor)
- Lack of knowledge--identified as barrier (also act as a facilitator)
- WAYS OF COPING (how do we address this, i.e. not an obvious 'barrier')
  - Avoidance/denial
  - Differences in information seeking/preferences



## BARRIERS

| Theme  | Codes (MG)   | Codes (SP)   | Codes (HL)   |
|--|--|--|--|
| <b>Don't know or incomplete knowledge about what cancer genetic counseling &amp; GT are</b><br><br><b>I. MISINFORMED &amp; UNIFORMED about cancer GC &amp; GT and the difference between GC and GT #1-priority</b>   | <ul style="list-style-type: none"> <li>• Lack of knowledge of what GC is or purpose of GC (10)</li> <li>• Misinformation (4)</li> <li>• Lack of provider information, education or suggestions of GC (3)</li> <li>• No expert to talk to (1)</li> <li>• Lack of knowledge about what test is (1)</li> <li>• Attention to breast cancer but not ovarian cancer (1)</li> <li>• Lack of knowledge about ovarian cancer (1)</li> <li>• GC vs. GT (difference) (1)</li> </ul> | <ul style="list-style-type: none"> <li>• Lack of or incomplete information (14)</li> <li>• Doesn't know what GC is (4)</li> <li>• Provider(s) did not discuss (2)</li> <li>• Belief that GC/GT is controversial (1)</li> <li>• Provider did not take male family history (1)</li> <li>• Not informed about age and cancer (1)</li> <li>• Misinformed re: cancer and family (1)</li> </ul>  | <ul style="list-style-type: none"> <li>• Doesn't know what GC is (6)</li> <li>• Don't know difference between GC and GT (1)</li> </ul>                           |
| <b>Fear of information/what to do with information</b><br><br><b>II. INFORMATION IMPACT (or Consequence) : fear, distress, uncertainty about knowing</b>   | <ul style="list-style-type: none"> <li>• Does not want information (1)</li> <li>• Fear of having breast(s) removed (1)</li> <li>• Preconceived ideas (negative) (1)</li> <li>• Fear of information (1)</li> <li>• How others will view you with diagnosis (1)</li> <li>• Emotional distress (1)</li> </ul>   | <ul style="list-style-type: none"> <li>• Fear (7)</li> <li>• Avoid/don't want to know (5)</li> <li>• Information will change how live life/depression (4)</li> <li>• Catastrophic thinking, afraid of results (4)</li> <li>• Negative attitude/closed mind (3)</li> <li>• Information can be overwhelming (1)</li> <li>• Fear regarding recurrence (1)</li> <li>• Genetic knowledge is burdensome (1)</li> <li>• Fear of death (cancer = death) (1)</li> <li>• Wanting information vs. actively seeking (1)</li> </ul> | <ul style="list-style-type: none"> <li>• Fear of discovering/knowing (5)</li> </ul>  |
| <b>Family issues/ communication</b><br><br><b>III. FAMILY CULTURE AND COMMUNICATION STYLE (CULTURAL ATTITUDES &amp; BELIEFS: family, spiritual, community)</b>   | <ul style="list-style-type: none"> <li>• Family history unknown or not discussed (4)</li> <li>• Unknown family hx (I. MISINFORMED)</li> <li>• Family hx not discussed (CULTURAL ISSUE)</li> <li>• Some family members may want test, others may not (2)</li> <li>• Relaying information to family who live in different locations (1)=PRACTICAL ISSUE)</li> </ul>  | <ul style="list-style-type: none"> <li>• Family doesn't want to discuss/ other issues taking priority (4) (FAMILY CULTURE)</li> <li>• Family history unknown (I. MISINFORMED)</li> <li>• / cancer not shared (3) (FAMILY CULTURE)</li> <li>• Family members afraid of genetic information (2) (INFORMATION IMPACT)</li> <li>• Parent dying of cancer (1)</li> <li>• Role conflict/ caregiver (1)</li> </ul>  | <ul style="list-style-type: none"> <li>• Family member does not want to know (1) (FAMILY CULTURE)</li> <li>• Don't know family history (1)</li> </ul>            |
| <b>Cost/financial concerns</b><br><br><b>V. LOGISTICS: insurance, employment, how to find services, ways to inform family/HOW TO ISSUES (e.g., what is the cost, what is your insurance coverage, what does your insurance do about pre-existing conditions; how to advocate yourself to insurance</b> | <ul style="list-style-type: none"> <li>• Financial (3)</li> <li>• Insurance coverage/cost (3)</li> </ul>   | <ul style="list-style-type: none"> <li>• Insurance/Cost (4)</li> <li>• Insurance coverage/ pre-existing condition (2)</li> </ul>   | <ul style="list-style-type: none"> <li>• Cost (4)</li> <li>• Insurance coverage/cost (1)</li> <li>• Advocate for your own care for insurance coverage</li> </ul> |

|   |  |  |  |
|---|--|--|--|
| <b>company)</b>   |  |  |  |
| <b>Employment/<br/>insurance discrimination/<br/>logistics.</b>   | <ul style="list-style-type: none"> <li>● Fear of insurance discrimination (3)</li> <li>● Discrimination from employers (1)</li> </ul>  | <ul style="list-style-type: none"> <li>● Employment discrimination (1)</li> </ul>  | <ul style="list-style-type: none"> <li>● Insurance discrimination (1)</li> </ul>   |
| <b>Lack of experience with or fear<br/>of technology</b>  | <ul style="list-style-type: none"> <li>● Doesn't use cell phone, fear of cell phone (3)</li> <li>● Fear of computer/lack of computer experience (2)</li> <li>● Fear of using mobile phone to track information (2)</li> <li>● Small screen on phone (2)</li> <li>● Fear/dislike of technology among elderly (1)</li> </ul> | <ul style="list-style-type: none"> <li>● "Too old" for technology (2)</li> <li>● Fear of cell phone/technology (2)</li> <li>● Hard to read on small screen (1)</li> </ul>  | <ul style="list-style-type: none"> <li>● Feel afraid of using technology</li> <li>● Not knowing how to use cell phone or computer</li> <li>● Small font/small screen-hard to read</li> </ul> |
| <b>Accessibility V. LOGISTICS)</b>  | <ul style="list-style-type: none"> <li>● Accessibility/locations (2)</li> </ul>  | <ul style="list-style-type: none"> <li>●</li> </ul>  | <ul style="list-style-type: none"> <li>●</li> </ul>  |
| <b>Religion/Cultural Fatalism</b><br><b>III. (CULTURAL BELIEFS)</b>   | <ul style="list-style-type: none"> <li>● God's will (religion/culture) (1)</li> </ul>  | <ul style="list-style-type: none"> <li>● Cultural attitudes/don't talk about cancer (2)</li> <li>● God's will (1)</li> <li>● Fatalistic attitude (1)</li> <li>●</li> </ul>   | <ul style="list-style-type: none"> <li>● Cultural beliefs/don't talk about cancer (3)</li> <li>● Feeling immoral about "knowing" what is going to happen, don't want results (3)</li> </ul>  |
| <b>Want to "move on" from cancer<br/>and treatment</b><br><br><b>V. CANCER-RELATED<br/>cultural attitudes and beliefs</b>   | <ul style="list-style-type: none"> <li>● Want treatment behind and move forward (1)</li> </ul>   | <ul style="list-style-type: none"> <li>● Have cancer behind you (2)</li> <li>● Done with treatment (1)</li> </ul>  | <ul style="list-style-type: none"> <li>● Negative feelings associated with ovarian cancer (1)</li> </ul>   |
| <b>Belief it is not relevant/ useful<br/>for them or no kids</b>  | <ul style="list-style-type: none"> <li>● No kids, not relevant (3)</li> <li>● Not going to pursue unless get another cancer (1)</li> <li>● Invincible, younger believe cancer isn't going to happen to them (1)</li> <li>● Belief there is nothing to be done with the information (1)</li> </ul>                          | <ul style="list-style-type: none"> <li>● No children, not relevant (2)</li> <li>● Information/ awareness is not enough (1)</li> <li>● No answers (1)</li> <li>● Perception of risk/ statistics (1)</li> <li>● Doesn't feel her cancer is hereditary (1)</li> <li>● Youthful beliefs in being impervious (1)</li> </ul> | <ul style="list-style-type: none"> <li>● Lack of information re: impact on other family members (2)</li> <li>● No children (2)</li> </ul>  |
| <b>TIMING, treatment related<br/>concerns</b><br><b>IV. CANCER-RELATED<br/>experiences: ill, overwhelmed,<br/>busy, medication fog, chemo<br/>brain; these then effect timing<br/>of resource-use.</b><br><b>Not during the treatment</b> | <ul style="list-style-type: none"> <li>● Overwhelmed at time of diagnosis (4)</li> <li>● Chemo brain/ medication fog (2)</li> <li>● Not feeling well (1)</li> <li>● Surgery too quick (1)</li> <li>● Too much information at diagnosis (1)</li> </ul>  | <ul style="list-style-type: none"> <li>● Timing (4)</li> <li>● Fatigue (1)</li> <li>● Chemo brain / memory (1)</li> <li>● Not feeling well (1)</li> </ul>  | <ul style="list-style-type: none"> <li>● Overwhelmed/busy with treatment (4)</li> <li>● Chemo brain (1)</li> </ul>   |
| <b>Guilt regarding GT</b><br><br><b>III. CULTURAL BELIEFS:<br/>should's, ought's, blame<br/>(assoc with Judeo-Christian or<br/>Western cultural belief system)</b>  | <ul style="list-style-type: none"> <li>● Blame the carrier of the gene (1)</li> <li>● Guilt that "should" be tested (1)</li> </ul>   | <ul style="list-style-type: none"> <li>● Should/ ought/ must re: GC and GT (3)</li> <li>● Parent's attitude/ blame (1)</li> </ul>  | <ul style="list-style-type: none"> <li>● Guilt / "should" do (1)</li> </ul>  |

## FACILITATORS

| Theme  | Codes (MG)   | Codes (SP)  | Codes (HL)  |
|--|--|---|---|
| <b>Information<br/>Topic I.</b>                | <ul style="list-style-type: none"> <li>• New, better tests available now (1)</li> <li>• GC/GT information is useful, can do something (1)</li> </ul>   | <ul style="list-style-type: none"> <li>• Information (2)</li> <li>• Benefits (1)</li> <li>• Catch cancer earlier (1)</li> <li>• Avoid cancer and cancer treatment (1)</li> <li>• Can take action (1)</li> </ul> | <ul style="list-style-type: none"> <li>• Avoid future cancer (1)</li> </ul>   |
| <b>Family<br/>Topic II and III.</b>            | <ul style="list-style-type: none"> <li>• Concern for family members (3)</li> <li>• Family members knowledgeable about family history (2)</li> <li>• Family members want to know (1)</li> </ul> | <ul style="list-style-type: none"> <li>• Family/ altruistic belief (5)</li> <li>• Granddaughter/ family (3)</li> </ul>  | <ul style="list-style-type: none"> <li>• Benefit family members (6)</li> <li>• Sharing with family (1)</li> <li>• Document family history for future generations (1)</li> </ul> |
| <b>Personal Characteristics<br/>Topic III.</b> | <ul style="list-style-type: none"> <li>• Information seeker (2)</li> <li>• Having control (1)</li> <li>• Curiosity (1)</li> </ul>  | <ul style="list-style-type: none"> <li>• This is something you can control (1)</li> <li>• Curiosity (1)</li> <li>• Information seeking (1)</li> <li>• Assigning positive value to results of GT (1)</li> </ul>  | <ul style="list-style-type: none"> <li>• information seeking</li> </ul>   |
| <b>Timing</b>                                  | <ul style="list-style-type: none"> <li>• Good health (info prior to ovarian cancer) (1)</li> <li>• On own time, terms (1)</li> </ul>   | <ul style="list-style-type: none"> <li>• Fits your timing (2)</li> <li>• Learn before you are sick (1)</li> </ul>   | <ul style="list-style-type: none"> <li>• Timing (5)</li> <li>• Deliver information after aggressive treatment (1)</li> <li>• Information before sick (1)</li> </ul>             |
| <b>Triggers<br/>Topic V.</b>                   | <ul style="list-style-type: none"> <li>• Referral from physician (1)</li> </ul>  | <ul style="list-style-type: none"> <li>• Physician recommendation (1_</li> <li>• Posted information (1)</li> </ul>  | <ul style="list-style-type: none"> <li>• Doctor/ nurse reminder or recommendation (4)</li> <li>• Provide information of GC as part of physical check-up (1)</li> </ul>          |
| <b>Training</b>                                | <ul style="list-style-type: none"> <li>• Teach patients how to use app (1)</li> <li>• Provide written instructions (1)</li> </ul>  | <ul style="list-style-type: none"> <li>• Training on app (4)</li> </ul>   | <ul style="list-style-type: none"> <li>• Training on app</li> </ul>   |
| <b>Public stories</b>                          | <ul style="list-style-type: none"> <li>• Angelina Jolie story (1)</li> </ul>   | <ul style="list-style-type: none"> <li>• Someone familiar start conversation (Angelina Jolie) (1)</li> </ul>  | <ul style="list-style-type: none"> <li>• Angelina Jolie story (2)</li> </ul>  |
| <b>Practical</b>                               | <ul style="list-style-type: none"> <li>• Cost of GT is less than cancer treatment (2)</li> </ul>   | <ul style="list-style-type: none"> <li>• Save money by preventing cancer (2)</li> <li>• Insurance covers it (1)</li> </ul>  | <ul style="list-style-type: none"> <li>•</li> </ul>   |



## TOPICS TO INCLUDE

| Theme  | Codes (MG)   | Codes (SP)  | Codes (HL)   |
|--|--|---|--|
| <b>Information on Ovarian Cancer Topic I.</b>              | <ul style="list-style-type: none"> <li>Statistics, different from other cancers (2)</li> <li>Relationship between ovca, FT, PP (1)</li> <li>No good screening for ovarian cancer (1)</li> </ul>  | <ul style="list-style-type: none"> <li></li> </ul>  | <ul style="list-style-type: none"> <li>Information on ovca, symptoms (1)</li> <li>Easy to understand facts/stats (1)</li> </ul>  |
| <b>General Information on GC and GT Topic I.</b>           | <ul style="list-style-type: none"> <li>What GC is (1)</li> <li>What information can be provided (1)</li> <li>Sub-populations at risk (1)</li> <li>Links between cancers (1)</li> <li>Pros/cons of GC and GT (1)</li> <li>Difference between GC and GT (1)</li> <li>NCCN, SGO guidelines (1)</li> </ul> | <ul style="list-style-type: none"> <li>What is GC (1)</li> <li>Broad/general information (1)</li> <li>Frame GC as conversation about family medical history (1)</li> <li>Pros/cons of GC (1)</li> <li>Information re: associated cancers (1)</li> <li>Frame information in positive way (1)</li> <li>Sub-populations (1)</li> </ul> | <ul style="list-style-type: none"> <li>Benefits of GC (4)</li> <li>Information on BRCA (2)</li> <li>Information on GT (2)</li> <li>General information on genetics and disease (hereditary disease)</li> <li>What is GC (2)</li> <li>Pros/cons of GC, GT (2)</li> <li>Ashkenazi descent / sub-populations (1)</li> <li>Related cancers (1)</li> <li>National guidelines (1)</li> </ul> |
| <b>How information from GC and GT can be used Topic I.</b> | <ul style="list-style-type: none"> <li>Prevention methods (5)</li> <li>What GT results mean (1)</li> <li>Prevent future cancer (note: not 100%) (1)</li> <li>Treatment and BRCA status (ex. surgery, PARP inhibitors) (1)</li> </ul>   | <ul style="list-style-type: none"> <li>Prevention (not guarantee) (1)</li> </ul>  | <ul style="list-style-type: none"> <li>What actions can be taken to prevent future cancer (1)</li> <li>What positive or negative results mean (1)</li> </ul>   |
| <b>Why Relevant Topic II.</b>                              | <ul style="list-style-type: none"> <li>Relevance for family members (5)</li> <li>Relevance if don't have children (1)</li> <li>Relevance for patient (prevent future cancer) (1)</li> </ul>  | <ul style="list-style-type: none"> <li>Value of GC (1)</li> <li>Why GC is relevant, important (1)</li> </ul>  | <ul style="list-style-type: none"> <li>Relevance for family members, including males (1)</li> </ul>  |
| <b>Emotional Issues Topic II. and IV.</b>                  | <ul style="list-style-type: none"> <li>Fear of results (3)</li> <li>Concern about hope being taken away if positive test (1)</li> <li>Fear for family members (1)</li> </ul>   | <ul style="list-style-type: none"> <li>Fear (5)</li> <li>Attitude (1)</li> <li>New information can be overwhelming (1)</li> <li>Emotions associated with cancer, GC (1)</li> </ul>  | <ul style="list-style-type: none"> <li>Frame cancer as living with it, not a death sentence (1)</li> </ul>   |
| <b>Communicating with Family Topic III.</b>                | <ul style="list-style-type: none"> <li>Importance of mother and father's history (2)</li> <li>Communicate risks and results with family (1)</li> <li>How to involve family (1)</li> <li>What to do if adopted/little known about family history (1)</li> <li>Talking about cancer (1)</li> </ul>       | <ul style="list-style-type: none"> <li>How to share information with family (2)</li> <li>How to talk about cancer (1)</li> </ul>  | <ul style="list-style-type: none"> <li>How to share information with family (2)</li> <li>Importance of mother and father's family history (1)</li> </ul>   |
| <b>Practical Issues Topic V.</b>                           | <ul style="list-style-type: none"> <li>Referral process/ how to get appointment (1)</li> <li>Insurance coverage (1)</li> <li>Affordable Care Act (1)</li> </ul>  | <ul style="list-style-type: none"> <li>Where to find GC (2)</li> <li>How to prepare for GC appointment (1)</li> </ul>   | <ul style="list-style-type: none"> <li>Where to get GC (1)</li> <li>Health insurance coverage (1)</li> <li>Outline GC appointment (1)</li> </ul>   |



## FEATURES OF/RECOMMENDATIONS FOR MOBILE APPLICATION

| Theme  | Codes (MG)   | Codes (SP)  | Codes (HL)   |
|--|--|---|--|
| <b>Timing</b>                                  | <ul style="list-style-type: none"> <li>• Accessible when convenient (2)</li> <li>• When in an “ok” state (1)</li> <li>• On own time (1)</li> </ul>   | <ul style="list-style-type: none"> <li>• Timing (2)</li> <li>• Flexible re: when/where to use and time (2)</li> </ul>   | <ul style="list-style-type: none"> <li>• Available when want (1)</li> </ul>  |
| <b>Features</b>                                | <ul style="list-style-type: none"> <li>• Ability to go back and view later (4)</li> <li>• Ability to share with others (3)</li> <li>• FAQs (1)</li> <li>• Ability to email and get response (1)</li> <li>• Save information for future use (1)</li> <li>• Glossary to describe words/ dictionary (1)</li> <li>• Reminders (1)</li> <li>• Pop-ups (like updates)</li> <li>• Pictures</li> <li>• Where to find GC (1)</li> <li>• Quiz re: risk factors (1)</li> <li>• Videos of survivors telling stories of why they were tested (1)</li> <li>• Number to call (1)</li> </ul>   | <ul style="list-style-type: none"> <li>• FAQs (2)</li> <li>• As questions, get response (2)</li> <li>• Pictures (1)</li> <li>• Save information (1)</li> <li>• Explain terminology (1)</li> <li>• Reminders (1)</li> <li>• Pop-ups to trigger patient to look at app (1)</li> <li>• Quiz (1)</li> <li>• Share information with family (1)</li> </ul>  | <ul style="list-style-type: none"> <li>• FAQs (1)</li> <li>• Interactive questions/features (2)</li> <li>• Email to ask questions (1)</li> <li>• Ability to save information (1)</li> <li>• Dictionary (1)</li> <li>• GPS, GC locations (1)</li> <li>• Quiz/questions (1)</li> <li>• Available on computer (1)</li> <li>• Risk calculator (1)</li> <li>• Link to call someone available to answer questions (1)</li> <li>• game</li> </ul> |
| <b>Information Presentation</b>                | <ul style="list-style-type: none"> <li>• Accurate information (3)</li> <li>• Incremental information (2)</li> <li>• Short and sweet (2)</li> <li>• Personal/ relevant for user (2)/TAILOR</li> <li>• Careful what show in video/ do not want to see scary material (2)</li> <li>• Written material (1)</li> <li>• Broad information with link for more specific information (1)--TAILORING</li> <li>• Address different ways of learning (1)/TAILOR--ie for those of you who want more information, LINKS are provided.</li> <li>• Text and video (1)</li> <li>• Clear, non-medical language (1)</li> <li>• Do not invoke fear (1)</li> <li>• Not overwhelming (1)</li> <li>• Information and support (1)</li> </ul> | <ul style="list-style-type: none"> <li>• Positive messaging (3)</li> <li>• Written material (2)</li> <li>• Multi-media presentation of material (2)</li> <li>• Quality information (1)</li> <li>• Information in logical order (1)</li> <li>• Start light, like with game or quiz (1)</li> <li>• Features that “draw you in” (1)</li> <li>• Short text (1)</li> <li>• Not too much information (1)</li> </ul> | <ul style="list-style-type: none"> <li>• Videos (3)</li> <li>• Short text (3)</li> <li>• Pictures (2)</li> <li>• Avoid medical jargon (1)</li> <li>• Easy to understand (1)</li> <li>• Broad information then specific (1)</li> <li>• Use pictures as triggers (1)</li> <li>• Provide support (1)</li> <li>• Supportive and warm wordings</li> <li>• App to provide emotional support</li> </ul>   |
| <b>Technical Considerations</b>                | <ul style="list-style-type: none"> <li>• Easy access (2)</li> <li>• Simple (2)</li> <li>• Easy to use (1)</li> <li>• Tricks/ incentives to make people look more often (1)</li> <li>• Not too much scrolling (1)</li> <li>• Keep data load low (1)</li> </ul>  | <ul style="list-style-type: none"> <li>• Simple to use (2)</li> <li>• Easy access (1)</li> </ul>  | <ul style="list-style-type: none"> <li>• Simple (3)</li> <li>• Big font size (1)</li> </ul>  |
| <b>Training</b>                                | <ul style="list-style-type: none"> <li>• Training module (1)</li> </ul>  | <ul style="list-style-type: none"> <li>• Written instructions (2)</li> <li>• Training (1)</li> </ul>  | <ul style="list-style-type: none"> <li>• Written training manual (1)</li> </ul>  |
| <b>Connections to Other Websites/ Programs</b> | <ul style="list-style-type: none"> <li>• Connectivity with Outlook calendar (2)</li> <li>• Provide links to other credible websites (2)</li> </ul>   | <ul style="list-style-type: none"> <li>• Link to other websites (1)</li> </ul>  | <ul style="list-style-type: none"> <li>• Links to other website</li> </ul>   |



## Appendix H. Preliminary Intervention Messaging

Text Program: mMAGIC

### Introduction of the program

\*Including health navigator information:

## Day 1 (What Is Genetic Counseling)

| Timeslot | Text #   | Message   | Answer 1 | Answer 2 | Notes |
|----------|----------|---|----------|----------|-------|
| 18:00:00 | Greeting | <introduction><br>1. <b>DAY 1: Genetic Counseling</b> (Locate this at the center, big, bold)<br><br>[note: Day 1 flower under the title]  |          |          |       |
| 18:00:30 |          | 2. Hi <b>Name</b> ! Welcome to mMAGIC.<br><br>Thank you for participating. We appreciate your time and are here for you during this week and beyond.<br><br>Each day you will receive a short series of texts and watch one to two brief videos. After your daily session, you will see a flower. This means you have completed your day.<br><br>At the end of the seven days, you will have collected seven flowers and you will receive a gift card.<br><br>It's OK if you miss a text or video—you can always go back to that day and complete it within the week. |          |          |       |
|          |          | 3. If you have any questions or need help, please call the <b>health navigator at XXX-XXX-XXXX</b> .<br><br>Let's get started!  |          |          |       |

| Timeslot | Text # | Message | Answer 1 | Answer 2 | Notes |
|----------|--------|---------|----------|----------|-------|
|----------|--------|---------|----------|----------|-------|

|          |  |   |   |  |   |
|----------|--|---|---|--|---|
| 18:01:00 |  | <b>4. Have you heard about genetic counseling for cancer?</b><br><br>1) Yes<br>2) No  | IF YES<br><br>4. Great! Here's a little more information about it.<br><br>Genetic counseling is an office visit with a certified genetic counselor to review your family history of cancer.<br><br>Genetic counselors help you understand the complexities of genetics and assist you in making the right decision about genetic testing. | IF NO<br><br>4. No problem. Here's some information about it.<br><br>Genetic counseling is an office visit with a certified genetic counselor to review your family history of cancer.<br><br>Genetic counselors help you understand the complexities of genetics and assist you in making the right decision about genetic testing. | If no answer for 1.5 minutes, we give reminder text: Are you still there? We haven't received your answer yet ... |
|          |  | <b>5. Did you know that genetic counseling is recommended for all women who have had ovarian cancer in their lifetime?</b><br><br>1) Yes<br>2) No | IF YES<br><br>5. Excellent! Here's why.<br><br>National medical associations recommend that women who have ever had ovarian cancer have genetic counseling even without a family cancer history.  | IF NO<br><br>5. That's fine. Here's why.<br><br>National medical associations recommend that women who have ever had ovarian cancer have genetic counseling even without a family cancer history.  | If no answer for 1.5 minutes, we give reminder text: Are you still there? We haven't received your answer yet ... |

6. [insert video –two clips: first Melissa, second Kristin]

Click here to watch Dr. Geller, a gynecologic oncologist

Click here to watch Genetic Counselor Kristin Niendorf talk about who should see a genetic counselor.

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**MELISSA TOPICS**

- Discuss national guidelines (QUIZ ITEM)
- Discuss who goes: anyone with ovarian cancer. (QUIZ ITEM)
- Your medical provider may have recommended that you go. Maybe not. The important thing to remember is to call.
- You don't need a referral to make an appointment.

**KRISTIN TOPICS**

- More than one gene can cause ovarian cancer (QUIZ ITEM DAY 2)
- BRCA 1 & 2 often play a role in developing ovarian cancer (QUIZ ITEM DAY 2)
- About 15%-25% of ovarian cancer can be inherited (QUIZ ITEM)

Clues:

- Multiple cancers in closely related family members
- More than one generation affected by cancer
- Early onset of cancer (breast cancer at or below age 50)
- Unusual cancers (such as male breast cancer)
- Ashkenazi Jewish ancestry

Insurance

- Some women worry, "Will my insurance pay for counseling?" Your genetic counselor can help you figure this out.

A genetic counselor is a resource to help you care for yourself.

A little later, you will meet two women who have had ovarian cancer and received genetic counseling.

| Timeslot | Text #  | Message  | Answer 1   | Answer 2   | Notes  |
|----------|---------|--|--|--|--|
|          |         | <p><b>7. Do you know why genetic counseling is so strongly recommended?</b></p> <p>1) Yes<br/>2) No</p>  | <p>IF YES</p> <p>Superb! Key points are:</p> <ul style="list-style-type: none"> <li>About 15%-25% of all cases of ovarian cancer can be inherited (QUIZ ITEM)</li> <li>Ovarian cancer has a stronger hereditary link than many other cancers.</li> </ul> <p><u>For more information, click here to visit our website</u></p> | <p>IF NO</p> <p>That's OK! Key points are:</p> <ul style="list-style-type: none"> <li>About 15%-25% of all cases of ovarian cancer can be inherited (QUIZ ITEM)</li> <li>Ovarian cancer has a stronger hereditary link than many other cancers.</li> </ul> <p><u>For more information, click here to visit our website</u></p> | <p>If no answer for 1.5 minutes, we give reminder text: Are you still there? We haven't received your answer yet ...</p> |
|          |         | <p>8. [insert video with Amy]</p> <p>Click here to watch Amy, a woman who has had ovarian cancer, talk about her experiences with genetic counseling</p> <ul style="list-style-type: none"> <li>Identify hesitancy/fears</li> <li>Describe how she did to cope with action steps</li> <li>Share positive experiences</li> <li>Proactive for their health and family</li> <li>Support and promote using the mobile app/phone</li> </ul>             |  |  |  |
|          | Summary | <p><b>9. You've learned a lot today! Here is a summary of Day 1:</b></p> <ul style="list-style-type: none"> <li>Genetic counseling is an office visit with a certified genetic counselor to review your family history of cancer.</li> <li>National medical associations recommend that women who have ever had ovarian cancer have genetic counseling even without a family history.</li> <li>About 15%-25% of cases of ovarian cancer</li> </ul> |  |  |  |

|  |  |  |  |  |  |
|--|--|--|--|--|--|
|  |  | <p>can be inherited.</p> <p>Genetic counseling will help you decide whether to have genetic testing—that’s a benefit!</p>  |  |  |  |
|  |  | <p><b>10. Great job! You completed Day 1. Click <a href="#">HERE</a> to receive your first flower.</b></p> <p>[FLOWER APPEARS AFTER CLICK]</p>                       |  |  | <p>If no answer for 1.5 minutes, we give reminder text: Are you still there? We haven’t received your answer yet ...</p> |
|  |  | <p><b>11. Get ready for Day 2!</b></p> <p>On Day 2, we’ll discuss genetic testing, its pros and cons and how it can positively affect your wellness. Stay tuned!</p> |  |  |  |



## Day 2 (Genetic Testing)

| Timeslot | Text # | Message   | Answer 1   | Answer 2  | Notes |
|----------|--------|---|--|---|-------|
|          |        | <p>&lt;Greeting&gt;</p> <p>1. <b>DAY 2: Genetic Testing</b> (Locate this at the center, this should be large and bold)</p> <p>[Day 2 flower under text]</p> |  |   |       |
|          |        | <p>2. Welcome to Day 2, <b>NAME</b>! Today we'll talk about how genetic counselors can help you with genetic testing.</p> <p>OK, let's go!</p>              |  |   |       |
|          |        | <p><b>3. Have you heard about genetic testing for cancer?</b></p> <p>1) Yes<br/>2) No</p>   | <p>IF YES</p> <p>3. Fantastic! Let's go a little deeper.</p> <p>Genetic testing is a blood test that looks at your DNA, the blueprint of your body.</p> <p>The goal of genetic testing is to find out if your ovarian cancer is linked to a cancer gene.</p> <p>If there is a link, then your health care providers can help you and your family reduce your risk of future cancers.</p> | <p>IF NO</p> <p>2. No problem! Here's what you should know.</p> <p>Genetic testing is a blood test that looks at your DNA, the blueprint of your body.</p> <p>The goal of genetic testing is to find out if your ovarian cancer is linked to a cancer gene.</p> <p>If there is a link, then your health care providers can help you and your family reduce your risk of future cancers.</p> |       |

| Timeslot | Text # | Message  | Answer 1   | Answer 2  | Notes |
|----------|--------|--|--|---|-------|
|          |        | <b>4. Do you know how genes are linked to ovarian cancer?</b><br>1) Yes<br>2) No   | IF YES<br><br>Great! Here's some background.<br><br>BRCA1 and BRCA2 are genes linked to increased risk of ovarian, breast and other cancers.<br><br>There are other genes that can cause hereditary ovarian cancer, too. | IF NO<br><br>Don't worry, here's some background.<br><br>BRCA1 and BRCA2 are genes linked to increased risk of ovarian, breast and other cancers.<br><br>There are other genes that can cause hereditary ovarian cancer, too. |       |
|          |        | 5. [Graph of BRCA1 & BRCA2 penetrance. Voiceover Kristin.]   |  |   |       |
|          |        | <b>6. I've already had ovarian cancer. Why would I have a genetic test?</b><br><br>Testing will help you and your family members take steps to reduce future cancers.<br><br>Usually, the best person to test first in a family is the person with cancer.<br><br>If a cancer gene is found in a person with cancer, we know it's linked to their cancer.<br><br>This makes testing simpler and less expensive for other family members. |  |   |       |

| Timeslot | Text # | Message   | Answer 1  | Answer 2   | Notes |
|----------|--------|---|---|--|-------|
|          |        | <b>7. What comes first? Genetic testing or seeing a genetic counselor?</b><br><br>1) Genetic testing<br>2) Seeing a genetic counselor   | IF 1<br><br>7. You're correct!<br><br>Seeing a certified genetic counselor is the best first step.<br><br>She or he will help you get the right test for your family history.<br><br>Genetic counselors also help you understand your results and guide you on your next steps.<br><br>They will support you if you feel worried.<br><br>Most important, you are NOT alone! | If 2<br><br>7. Actually, seeing a certified genetic counselor is the best first step.<br><br>She or he will help you get the right test for your family history.<br><br>Genetic counselors also help you understand your results and guide you on your next steps.<br><br>They will support you if you feel worried.<br><br>Most important, you are NOT alone! |       |
|          |        | [VIDEO] of Shannon discussing results of genetic testing and how it helped her and her family <ul style="list-style-type: none"> <li>• Understand risk</li> <li>• Action steps</li> <li>• Reduce family cost</li> <li>• Opened the conversation with my family</li> </ul> |   |  |       |
|          |        | <b>8. If you have any questions or need help, please call the health navigator XXXXX XXXXXXXX at 612-624-XXXX.</b>  |   |  |       |

| Timeslot | Text #  | Message   | Answer 1 | Answer 2 | Notes |
|----------|---------|---|----------|----------|-------|
|          | Summary | <p><b>9. Genetic testing is a complex topic! Great job. Here is a summary of Day 2:</b></p> <ul style="list-style-type: none"> <li>• Genetic testing is a blood test that looks at your DNA, the blueprint of your body.</li> <li>• BRCA1 and BRCA2 are genes linked to increased risk of ovarian, breast and other cancers.</li> <li>• Usually, the best person to test first in a family is the person with cancer.</li> <li>• If your genetic test shows your ovarian cancer is linked to a cancer gene, then your health care providers can help you and your family reduce your risk of future cancers.</li> <li>• Genetic counselors can help you before, during and after genetic testing</li> </ul> |          |          |       |
|          |         | <p><b>10. Fabulous! You completed Day 2. Click <a href="#">HERE</a> to receive your second flower.</b></p> <p>[FLOWER APPEARS AFTER CLICK]</p>  |          |          |       |
|          |         | <p><b>11. Get ready for Day 3</b></p> <p>On Day 3, we'll talk about how genetic testing can impact your personal health and how you can rely on your genetic counselor. See you soon!</p>   |          |          |       |

## Day 3: Cancer Genetics and Personal Health

| Timeslot | Text # | Message   | Answer 1   | Answer 2   | Notes  |
|----------|--------|---|--|--|--|
|          |        | <p>&lt;Greeting&gt;</p> <p>1. <b>DAY 3: Cancer Genetics and Personal Health</b><br/>(Locate this at the center, this should be large and bold)</p> <p>[Day 3 flower under text]</p> |  |  |  |
|          |        | <p>2. Welcome to Day 3, <b>NAME</b>! Today we'll discuss how cancer genetics can affect your health.</p> <p>Off we go!</p>  |  |  |  |
|          |        | <p><b>3. : If I have an altered gene for cancer does it mean I will get another cancer?</b></p> <p>1) Yes<br/>2) No</p>   | <p>IF YES</p> <p>1. Actually, it's not a guarantee. But it does increase your chances.</p> <p>Your mother or father can pass down an altered BRCA gene to you even if they didn't have cancer.</p> <p>When you have an altered BRCA gene, it doesn't mean you will get cancer. It means it's more likely. This applies to your brothers and sisters, too. They each have a 50% chance of inheriting an altered gene.</p> | <p>IF NO</p> <p>2. It's not certain, but having the altered gene can increase your chances of another cancer</p> <p>Your mother or father can pass down an altered BRCA gene to you even if they didn't have cancer.</p> <p>When you have an altered BRCA gene, it doesn't mean you will get cancer. It means it's more likely. This applies to your brothers and sisters, too. They each have a 50% chance of inheriting an altered gene.</p> | <p>If no answer for 1.5 minutes, we give reminder text: Are you still there? We haven't received your answer yet ...</p> |



| Timeslot | Text # | Message  | Answer 1 | Answer 2 | Notes |
|----------|--------|--|----------|----------|-------|
|          |        | <p><b>4. What happens if I have an altered gene?</b></p> <p>When you have had ovarian cancer and an altered gene is found, your genetic counselor can help you understand what you can do.</p> <ol style="list-style-type: none"> <li>1. More frequent cancer screening may be recommended.</li> <li>2. There are some medications or procedures to decrease the likelihood of future cancers.</li> <li>3. Knowing your hereditary risk could change how your ovarian cancer or other cancers are treated.</li> </ol>  |          |          |       |
|          |        | <p><b>[VIDEO]</b> Dr. Anne Blaes talks about screening and treatment for ovarian cancer survivors</p> <ul style="list-style-type: none"> <li>• Screening—what is it? (to detect cancers earlier) <ul style="list-style-type: none"> <li>○ Ovarian screening and its limitations</li> <li>○ Pelvic ultrasounds, CA125 (every 6 mo.)</li> <li>○ Breast screening—mammogram and MRI every six months</li> <li>○ Colonoscopy as a way to identify and remove polyps before they turn into cancer</li> </ul> </li> <li>• Prevention— <ul style="list-style-type: none"> <li>- Prophylactic mastectomy</li> <li>- Prophylactic BSO</li> <li>- Chemo prevention</li> <li>- Other prophylactic measures</li> </ul> </li> </ul> |          |          |       |

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|  |  | <b>5. Is it important for family members to know the results of genetic testing?</b> <ol style="list-style-type: none"> <li>Yes</li> <li>No</li> </ol> | <p>IF YES</p> <ol style="list-style-type: none"> <li>We agree! It's important because talking about hereditary cancer will help family members be more aware of their own health and take action.</li> </ol> <p>We'll talk more about family in Day 4.</p> | <p>IF NO</p> <ol style="list-style-type: none"> <li>Actually, it can be helpful to talk with your family.</li> </ol> <p>Some women talk as little as possible about their cancer—they worry that it will upset family.</p> <p>But, talking about hereditary cancer will help family members be more aware of their own health and take action.</p> <p>We'll talk more about family in Day 4.</p> | <p>If no answer for 1.5 minutes, we give reminder text: Are you still there? We haven't received your answer yet ...</p> |
|--|--|--|--|--|--|

|  |         |  |                  |  |  |
|--|---------|--|------------------|--|--|
|  | Summary | <b>6. This was a big day to tackle! Here's a summary of what we covered:</b> <p>BRCA1 and BRCA2 are known as the breast cancer genes. These are the most common gene mutations associated with ovarian cancer. There are other gene alterations that cause ovarian cancer but these happen less often.</p> <p>Knowing your hereditary risks may help guide your future cancer screening, medication, procedures or even cancer treatment.</p> <p>Talking with your family about cancer and cancer genetics is a way for them to understand their cancer risks.</p> | HEEWON TO UPDATE |  |  |
|--|---------|--|------------------|--|--|

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|  |  | <b>10. Beautiful! You completed Day 3. Click <a href="#">HERE</a> to receive your third flower.</b><br><br>[FLOWER APPEARS AFTER CLICK] |  |  |  |
|  |  | <b>11. Get ready for Day 4</b><br>Day 4 will be about talking with your family about hereditary cancers. Stay tuned!                    |  |  |  |

## Day 4: Cancer Genetics and My Family

| Timeslot | Text # | Message   | Answer 1   | Answer 2  | Notes  |
|----------|--------|---|--|---|--|
|          |        | <p>&lt;Greeting&gt;</p> <p>1. <b>DAY 4: Cancer Genetics and My Family</b><br/>(Locate this at the center, this should be large and bold)</p> <p>[Day 4 flower under text]</p>   |  |   | Even if the result is negative, meaning you do not have a gene mutation, it is important to share this result. |
|          |        | <p>2. Welcome to Day 4, <b>NAME</b>! Today's about talking with your family about hereditary cancer.</p> <p>Let's get started!</p>  |  |   |  |
|          |        | <p>3. Here are some myths:</p> <ul style="list-style-type: none"> <li>• I am adopted so genetic counseling won't help me.</li> <li>• I don't have children so genetic counseling won't help me.</li> <li>• I don't know my family history so a genetic counselor can't help me.</li> <li>• Cancer runs in my father's side and therefore won't affect me.</li> <li>• Men cannot inherit ovarian cancer genes.</li> <li>• Women cannot get ovarian cancer if there is no family history of ovarian cancer.</li> </ul> <p>Did you know these are myths?</p> <ol style="list-style-type: none"> <li>1. Yes</li> <li>2. No</li> </ol> | <p>If yes</p> <p>Good for you! These myths often prevent people from seeing a genetic counselor.</p> <p>You don't need to know your family history to benefit from genetic counseling. Genes come from your mom and dad and the risk of hereditary cancer can affect both men and women.</p> | <p>If NO</p> <p>Actually, these myths often prevent people from seeing a genetic counselor.</p> <p>You don't need to know your family history to benefit from genetic counseling. Genes come from your mom and dad and the risk of hereditary cancer can affect both men and women.</p> |  |

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|  |  | <p>4. Some women believe finding out they have a hereditary cancer gene is a death sentence.</p> <p>It's NOT. While there is an increased risk of getting a hereditary cancer, the reality is that people with an altered gene may not ever develop a cancer.</p> <p>What is known is that seeing a genetic counselor can help decrease the risk of future cancers.</p> |  |   |   |
|  |  | <p>5. What you've learned this week is important to share. Have you talked with your family about what you've learned using the mobile app?</p> <p>1. Yes<br/>2. No</p>   | <p>IF YES and went well</p> <p>1. Good for you! How did it go?</p> <p>a. It went well<br/>b. It could have been better</p> <p>Fantastic! Next, you'll see a video that offers a few ideas about how to talk with family if you ever get stuck.</p> | <p>IF YES and did not go well</p> <p>1. Good for you! How did it go?</p> <p>a. It went well<br/>b. It could have been better</p> <p>It can be hard to talk with your family about inherited cancer.</p> <p>Sometimes family members don't want to know about their chances of getting cancer.</p> <p>Others may be misinformed about cancer screening.</p> <p>You may worry that bringing up hereditary cancer could cause fear.</p> <p>Discussion may encourage your family to</p> | <p>IF NO</p> <p>2. It's OK—we can help you begin the conversation.</p> <p>It can be hard to talk with your family about inherited cancer.</p> <p>Sometimes family members don't want to know about their chances of getting cancer.</p> <p>Others may be misinformed about cancer screening.</p> <p>You may worry that bringing up hereditary cancer could cause fear.</p> <p>Discussion may encourage your family to be more open.</p> |



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|  |  |  |  | be more open. |  |
|  |  | <b>VIDEO #1:</b> conversations with your family<br><br>Here is a genetic counselor talking about conversation starters. Voiceover by Kristin; conversation starters (who are you closest to, who have you told about your cancer), see letter prompts, email template, family member point person, pedigree, etc. Family in remote locations-<br>-how to get info to them. |  |               |  |
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|  |  | <b>VIDEO Decision making and me. [Women's stories]</b> How to go ahead in spite of barriers. How others problem solve these issues. | <b>VIDEO#3:</b> Shannon video (maybe edit out the crying?) | PLACE THIS! |  |
|--|--|---|--|-------------|--|

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|--|---------|---|--|--|--|
|  | Summary | <p><b>6. You've learned some great things today!</b></p> <p>The decision to have genetic testing is yours to make.</p> <p>There are pros and cons to having genetic counseling and testing.</p> <p>We can help you find a genetic counselor to help guide you through the process.</p> <p>TELEPHONE LINK</p> <p><b>NEED TO UPDATE THIS ONCE DAY 4 IS SET.</b></p> |  |  |  |
|  |         | <p><b>7. Lovely! You completed Day 4. Click <b>HERE</b> to receive your fourth flower.</b></p> <p>[FLOWER APPEARS AFTER CLICK]</p>  |  |  | <p>If no answer for 1.5 minutes, we give reminder text: Are you still there? We haven't received your answer yet ...</p> |
|  |         | <p><b>8. Get ready for Day 5</b></p> <p>On Day 5, we'll address the emotions that can accompany genetic testing. Hang in there, you're doing great!</p>   |  |  |  |

## Day 5: Taking Care of Yourself

| Timeslot | Text #   | Message   | Answer 1 | Answer 2 | Notes |
|----------|----------|---|----------|----------|-------|
| 18:00:00 | Greeting | <p>&lt;introduction&gt;</p> <p>1. <b>DAY 5: Taking Care of Yourself</b> (Locate this at the center, big, bold)</p> <p>[note: Day 5 flower under the title]</p>  |          |          |       |
| 18:00:30 |          | <p>2. Welcome to Day 5, NAME! Today, we'll talk about how you may react to having genetic counseling and testing.</p> <p>OK, let's go!</p>  |          |          |       |
|          |          | <p>3. <b>It's OK to worry about hereditary cancer.</b></p> <p>You may be afraid of hearing the information, or afraid of hearing the results. You may think you will be overwhelmed or that knowing will change how you live your life.</p> <p>But by knowing, you can positively change your life. You may be able to reduce the risk of future cancers for both you and your family.</p> <p><b>VIDEO #1.</b> Health provider encouraging women to make an appt and managing their worry about it. DONA MAKI, Nurse Practitioner</p> <ul style="list-style-type: none"> <li>• Some examples of women worrying about hereditary cancer</li> <li>• Provide examples of managing the worry (bringing family members, creating support network, research, etc.)</li> <li>• Positive ways that counseling can help lives</li> <li>• Encourage making appointment</li> </ul> |          |          |       |

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|  |  | <p>4. Facing hereditary cancer can be challenging. How are you taking care of yourself?</p> <p><b>Choose one answer that describes you best:</b></p> <ol style="list-style-type: none"> <li>1. I am taking good care of myself</li> <li>2. I could take better care of myself</li> </ol>  | <p>IF 1</p> <p>1. Congratulations!</p> <p>You're doing a great job. If you want some effective methods for self-care, <a href="#">download a PDF of the "Worry-less Toolkit."</a></p> <p>[Toolkit or navigator provides information about:]</p> <ul style="list-style-type: none"> <li>• Doing a relaxing activity, such as reading</li> <li>• Acupuncture</li> <li>• Exercising</li> <li>• Deep breathing</li> <li>• Meditating</li> <li>• Getting plenty of sleep</li> <li>• Talking or walking with friends</li> <li>• Prayer</li> <li>• Talking with your doctor</li> <li>• Talking with your psychologist</li> <li>• Online or in-person support groups</li> </ul> | <p>IF 2</p> <p>2. That's OK—it can be difficult to take good care of yourself during this time.</p> <p>If you want some effective methods for self-care, <a href="#">download a PDF of the "Worry-less Toolkit."</a></p> <p>Same list</p> | <p>If no answer for 1.5 minutes, we give reminder text: Are you still there? We haven't received your answer yet ...</p> |
|  |  | <p>5. Don't forget about the value of support from friends and family. Support groups, a counselor or spiritual advisor can help you get through the tough times.</p> <p><b>VIDEO #2</b> : Quick snippets of how people received and asked for support</p> <p>Stories of coping with worry, avoidance, etc. Overall theme of how she received support (family, friends, pastor, psychologist, support group, physician) or what she did to help herself</p> <p>NO RIGHT WAY</p> |   |   |  |

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|  |         | <p><b>6.</b> You have some tools and information for caring for yourself. Taking care of yourself and your family includes knowing your hereditary risk.</p> <p>Now, how are you feeling when you think about making an appointment for genetic counseling? (INTERACTIVE)</p> <p>Text the number that best fits you now:</p> <ol style="list-style-type: none"> <li>1. I'm ready to make an appointment</li> <li>2. I need more time or information before making an appointment.</li> </ol> | <p>IF 1</p> <p>Great! Call the health navigator and she can help you find a genetic counselor for you.<br/> <a href="#">TELEPHONE LINK</a></p> | <p>IF 2</p> <p>That's OK. There is more helpful information ahead. You also can call the health navigator to get more information<br/> <a href="#">TELEPHONE LINK</a></p> | <p>If no answer for 1.5 minutes, we give reminder text: Are you still there? We haven't received your answer yet ...</p> |
|  | Summary | <p><b>7.</b> Thanks for hanging in there, today! Here's what you learned:</p> <p>Fear and worry can interfere with wanting to know more about ovarian cancer and inherited risk.</p> <p>There are many tools to help you lower your worry. You may want to know more about these. <a href="#">CALL your navigator.</a></p>   | HEEWON TO DO SUMMARY   |   |  |
|  |         | <p><b>9. Great job! You completed Day 5. Click <a href="#">HERE</a> to receive your fifth flower.</b></p> <p>[FLOWER APPEARS AFTER CLICK]</p>  |  |   |  |



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|  |  | <p><b>11. Get ready for Day 6!</b></p> <p>Day 6 covers insurance and costs of genetic counseling and testing—stay tuned!</p> |  |  |  |
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## Day 6: Insurance and Costs

| Timeslot | Text #   | Message  | Answer 1 | Answer 2 | Notes |
|----------|----------|--|----------|----------|-------|
| 18:00:00 | Greeting | <p>&lt;introduction&gt;</p> <p>1. <b>DAY 6: Insurance and Costs</b> (Locate this at the center, big, bold)</p> <p>[note: Day 6 flower under the title]</p>   |          |          |       |
| 18:00:30 |          | <p>2. Welcome to Day 6, NAME! This week, you've learned a lot about genetic counseling and testing. Today we will talk about insurance and costs.</p> <p>Off we go!</p>  |          |          |       |
|          |          | <p>3. <b>I heard I can lose my insurance or my job if I get genetic testing, is that true?</b></p> <p>Here's the good news: now we have laws protecting against health insurance and employment discrimination.</p> <p>These laws do not protect against discrimination by life, disability or long-term health care insurances.</p> <p>For more information regarding genetic discrimination laws go to the National Human Genome Research Institute: <a href="http://www.genome.gov/10002077">http://www.genome.gov/10002077</a></p> <p>Your genetic counselor will walk you through the laws and what protections you have.</p> |          |          |       |
| Timeslot | Text #   | Message  | Answer 1 | Answer 2 | Notes |

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|  |  | <b>4. Would the cost of genetic counseling and testing keep you from making an appointment?</b><br><br>1. Yes<br>2. No | <b>IF 1</b><br><br><p>Actually, the cost can be lower than you might think. Here's some help in rethinking about it.</p> <p>Genetic counseling and genetic testing are two different bills.</p> <p>Genetic counseling is an office visit cost which is usually covered by insurance. You usually don't need a referral but you should always check with your insurance company to be sure.</p> <p>Genetic tests are more expensive than genetic counseling visits. However, your genetic counselor will help you figure out what you have to pay before the test is ordered.</p> | <b>IF 2</b><br><br><p>That's correct!</p> <p>Here are the details about the cost of genetic counseling and testing.</p> <p>Genetic counseling and genetic testing are two different bills.</p> <p>Genetic counseling is an office visit cost which is usually covered by insurance. You usually don't need a referral but you should always check with your insurance company to be sure.</p> <p>Genetic tests are more expensive than genetic counseling visits. However, your genetic counselor will help you figure out what you have to pay before the test is ordered.</p> | If no answer for 1.5 minutes, we give reminder text: Are you still there? We haven't received your answer yet ... |
|  |  |  |  |   |   |

| Timeslot | Text # | Message | Answer 1 | Answer 2 | Notes |
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|  |         | <p><b>5. Will my insurance pay for genetic testing?</b></p> <p>Many genetic tests are covered by insurance. If your insurance company won't cover all the costs, genetic testing companies usually have payment plans.</p> <p>Once you meet with your genetic counselor they will help you, including writing letters to your insurance company to cover recommended genetic tests.</p> <p>There are programs that provide free testing or reduced costs for families in need, your genetic counselor can help you find these. This is one of the many benefits of seeing a genetic counselor.</p> <p>If you are unsure, ask when you make your appointment. Put it on your need to know list.</p> |  |  |  |
|  |         | <p><b>VIDEO #1: lawyer doing mythbusting about insurance and legal explanations—Susan Wolf?</b></p>  |  |  |  |
|  | Summary | <p>6. Great! You made it through Day 6. Here's what you learned today.</p> <p>Scheduling your genetic counseling appointment is the important first step in getting the help you need with genetic testing costs and what laws exist to protect your genetic information.</p> <ul style="list-style-type: none"> <li>• Genetic counseling and genetic tests are two different bills</li> <li>• Your genetic counselor will help you look into insurance coverage for testing</li> <li>• Laws are in place to protect you</li> </ul> <p>CALL your navigator if you have questions or would like to learn how to schedule your</p>   |  |  |  |

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|  |  | appointment.   |  |  |   |
|  |  | <b>7. Awesome! You completed Day 6. Click <a href="#">HERE</a> to receive your sixth flower.</b><br><br>[FLOWER APPEARS AFTER CLICK]                                   |  |  | If no answer for 1.5 minutes, we give reminder text: Are you still there? We haven't received your answer yet ... |
|  |  | <b>11. Get ready for Day 7!</b><br><br>On our final day, we'll talk about how to make an appointment with a genetic counselor and how to prepare for your appointment. |  |  |   |



## Day 7: Getting Ready for your Appointment

| Timeslot | Text #   | Message  | Answer 1  | Answer 2   | Notes  |
|----------|----------|--|---|--|--|
| 18:00:00 | Greeting | <p>&lt;introduction&gt;</p> <p>1. <b>DAY 7: Getting Ready for Your Appointment</b> (Locate this at the center, big, bold)</p> <p>[note: Day 7 flower under the title]</p>  |   |  |  |
| 18:00:30 |          | <p>2. You made it to Day 7, <b>NAME</b>! Today we'll talk about making a genetic counseling appointment and how to prepare for it.</p> <p>Let's get moving!</p>  |   |  |  |
|          |          | <p>3. <b>Now that you have learned about genetic counseling for ovarian cancer, let's see what you are thinking about it: <u>TEXT US THE NUMBER OF YOUR ANSWER.</u></b></p> <p>1. I have never thought about genetic counseling</p> <p>2. I am undecided about genetic counseling</p> <p>3. I have decided I don't want to have genetic counseling</p> <p>4. I have decided I do want to have genetic counseling</p> | <p>If 1 or 2:</p> <p>Is there more information you need? Would you be willing to text us about what further information you need?</p> <p>Automatic text back, <b>THANK YOU FOR YOUR RESPONSE</b></p> <p>If you want to talk to the health navigator, <b>Call LINK.</b></p> <p><b>Thanks for answering our question!</b></p> | <p>If 3</p> <p>Would you be willing to text us why you don't want genetic counseling?</p> <p>Automatic text back, <b>THANK YOU FOR YOUR RESPONSE</b></p> | <p>If 4</p> <p>Great! <b>Thanks for answering our question!</b> You'll see more information about how to make an appointment next.</p> <p>*If no answer for 1.5 minutes, we give</p> |

|          |        |   |  |   | reminder text: Are you still there? We haven't received your answer yet  |
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| Timeslot | Text # | Message   | Answer 1   | Answer 2  | Notes  |
|          |        | <b>4. One last question, suppose your genetic counselor has told you that your risk is high enough to go ahead with genetic testing? Would you have the genetic test?</b> <ol style="list-style-type: none"> <li>Yes</li> <li>No</li> </ol> | <p>IF 1</p> <p>Would you be willing to text us why you answered yes that you would consider a genetic test?</p> <p>Automatic text back,<br/><b>THANK YOU FOR YOUR RESPONSE</b></p> <p>If you want to talk to the health navigator, <b>Call LINK.</b></p> | <p>IF 2</p> <p>Would you be willing to text us why you answered not, that you would consider a genetic test?</p> <p>Automatic text back,<br/><b>THANK YOU FOR YOUR RESPONSE</b></p> <p>If you want to talk to the health navigator, <b>Call LINK.</b></p> | <p>If no answer for 1.5 minutes, we give reminder text: Are you still there? We haven't received your answer yet ...</p> |

| Timeslot | Text # | Message   | Answer 1  | Answer 2   | Notes |
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|          |        | <b>6. If you wanted to make an appointment for genetic counseling, do you know who to call?</b> <ol style="list-style-type: none"> <li>Yes</li> <li>No</li> </ol> | <p>IF 1</p> <p>Great! Here's where you can go.</p> <p><b>First check with your insurance provider to see if you have coverage for genetic counseling:</b></p> | <p>IF 2</p> <p>No problem—we can help you find a place with genetic counseling.</p> <p><b>If you have insurance for genetic counseling:</b><br/>Great! You can go to any</p> |       |

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|  |  |  | <p>1. <b>If you have coverage:</b> <a href="#">CLICK HERE (GPS NAV)</a> and enter in your zip code and distance you are willing to drive.</p> <p>2. <b>If you don't have insurance coverage:</b> Don't worry, we will cover your costs for the genetic counseling portion here at UMN Health at the following locations:<br/>Minneapolis:<br/>University of Minnesota Medical Center, Maple Grove, Wyoming (MN), Edina or Burnsville<br/><a href="#">Call health navigator. CALL LINK</a></p> <p>3. <b>If you don't know if you have insurance coverage for genetic counseling or testing:</b> call the health navigator and she can direct you to the right person <a href="#">CALL LINK</a></p> | <p>location that sees cancer genetic counseling patients. <a href="#">CLICK HERE (GPS NAV)</a> and enter in your zip code.</p> <p><b>If you don't have insurance coverage:</b><br/>Don't worry, we can cover your costs for the genetic counseling portion here at UMN Health at the following locations: Minneapolis: University of Minnesota Medical Center, Maple Grove, Wyoming (MN), Edina or Burnsville<br/><a href="#">Call health navigator. CALL LINK</a></p> <p><b>If you don't know if you have insurance coverage for genetic counseling or testing:</b> call health navigator and she can direct you to the right person <a href="#">CALL LINK</a></p> |  |
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|  | Summary | <p><b>7. How do I prepare for my genetic counseling appointment?</b></p> <p>It's often helpful to have family history information before your appointment. <a href="#">Click here for a form</a> on collecting your family history of cancer.</p> | <p><b>VIDEO#1:</b> Genetic Counselor – Important points:</p> <ul style="list-style-type: none"> <li>● It's great if you gather your family history of cancer before your appointment. This includes: your siblings, children, nieces/nephews, parents, aunts/uncles, grandparents and first cousins</li> <li>● It's OK if you don't have all the information on everyone but if you can call someone who knows in your family, that would be really helpful</li> <li>● Be sure to know where a person's cancer started (primary site, if known) not where it spread</li> <li>● Ask what age the person was when they were diagnosed with cancer and what age they are now or age when they passed away</li> <li>● If anyone has had genetic testing, it's best to get a copy of the genetic test report and bring it to your appointment</li> <li>● You can bring anyone you want to your appointment, in fact it's usually helpful to have at least one other person there to help you remember all the details</li> <li>● Bring your insurance card to your appointment so the genetic counselor can look into your genetic testing</li> <li>● Your genetic counseling session will be about 60 minutes long and the genetic counselor will: <ul style="list-style-type: none"> <li>○ Go over your family history</li> <li>○ Tell you how likely she/he thinks the cancer is hereditary in your family</li> <li>○ Discuss which genetic conditions can cause the cancers in your family</li> <li>○ Talk to you about genetic testing including possible results, time</li> </ul> </li> </ul> |  |  |

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|  |  |  | frame, costs and the emotional impact <ul style="list-style-type: none"> <li>o Assist you with having your blood drawn or saliva sampled if you decide to have a genetic test</li> <li>o Schedule a follow-up appointment to discuss the meaning of your results and what this means for your health and your family.</li> </ul> |  |   |
|  |  | <b>8. Wow, you're nearly through! Since it's our last day, here is a summary of the key points from the week:</b> <ul style="list-style-type: none"> <li>•</li> <li>•</li> <li>•</li> <li>•</li> <li>•</li> <li>•</li> <li>•</li> </ul>              | If you want a copy of the summary of each day of the program <a href="#">CLICK HERE - PDF</a>  |  | VIDEO: Patient encouraging making appointment   |
|  |  | <b>9. What an accomplishment! You completed Day 7 and the entire mAGIC app. Click <a href="#">HERE</a> to receive your seventh flower. If you haven't completed all of the days, you can go back and finish.</b><br><br>[FLOWER APPEARS AFTER CLICK] |  |  | If no answer for 1.5 minutes, we give reminder text: Are you still there? We haven't received your answer yet ... |
|  |  | <b>11. Thank you so much for your participation! ETC.</b><br><br><b>HEALTH NAV LINK FOR QUESTIONS, REFER TO WEBSITE, REMINDER OF FOLLOW-UP SURVEYS, REMIND THEM THEY WILL RECEIVE A GIFT CARD</b>  |  |  |   |